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Writings in Gerontology

National Advisory
Council on Aging

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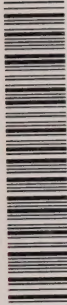
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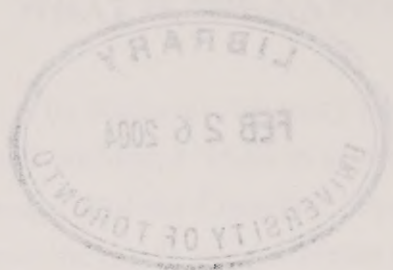


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MENTAL HEALTH AND AGING

October 2002

National Advisory Council on Aging

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The *Writings in Gerontology* present in-depth examinations of topical issues in the field of aging. The opinions expressed are those of the authors and do not necessarily imply endorsement by NACA.

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WHAT IS THE NATIONAL ADVISORY COUNCIL ON AGING?

The National Advisory Council on Aging (NACA) was created by Order-in-Council on May 1, 1980 to assist and advise the Minister of Health on issues related to the aging of the Canadian population and the quality of life of seniors. NACA reviews the needs and problems of seniors and recommends remedial action, liaises with other groups interested in aging, encourages public discussion and publishes and disseminates information on aging.

The Council has a maximum of 18 members from all parts of Canada. Members are appointed by Order-in-Council for two- or three-year terms and are selected for their expertise and interest in aging. They bring to Council a variety of experiences, concerns and aptitudes.

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- No. 8 Living with sensory loss, March 1990
- No. 13 Ethics and aging, February 1993
- No. 15 Aboriginal seniors' issues, March 1994
- No. 17 Seniors and technology, September 2001
- No. 18 Mental health and aging, October 2002

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FOREWORD

The *Writings in Gerontology* Series is intended as a vehicle for sharing ideas on topical issues related to the quality of life of seniors and the implications of an aging population. It is produced as part of the National Advisory Council on Aging's mandate to publish and disseminate information and to stimulate public discussion about aging.

The Council endeavours to ensure that the articles in the series provide useful and reliable information. The texts in this collection of *Writings* are original manuscripts written by experts in their fields. It is addressed to seniors, practitioners, caregivers and others who are concerned with seniors' well-being.

It is hoped that readers will find the *Writings* useful. The Council welcomes comments on the topics selected, as well as on the contents of the articles.

A handwritten signature in dark ink, reading "Nancy Garrard". The script is fluid and cursive, with the first letters of "Nancy" and "Garrard" being capitalized and prominent.

Nancy Garrard
Director
Division of Aging and Seniors

INTRODUCTION

The National Advisory Council on Aging is pleased to present this issue of *Writings in Gerontology* which focuses on the mental health of older adults. It follows a first publication (1991) with the same title, which was reprinted countless times to satisfy the demand for information on a subject of growing interest and concern.

While many of the issues surrounding older adults' mental health have not changed in the intervening 11 years, our knowledge and understanding of them have evolved. We are now much more aware, for example, that both physical and mental health are determined by a variety of interrelated factors beyond our biological make-up – social supports, physical environments, income, gender, coping skills, etc. We also have a much better appreciation of the importance of a positive approach to mental health, i.e. promoting good mental health rather than only treating poor mental health.

Because seniors are such a diverse population, it is clear that there cannot be a generic approach to promoting healthy aging and preventing or treating mental health problems. The contributors to this issue of the *Writings* present varying aspects of the question, from the general to the clinical and the particular. Yet an important notion underlies them all: mental health problems are not necessarily a part of aging. Rather, good mental health is possible for the majority of seniors given the right conditions and support.

NACA feels that seniors can only benefit from the dissemination of these discussions. We are grateful to the contributors for their valuable input to our understanding of the issues, needs and approaches related to seniors' mental health.

A handwritten signature in cursive script, reading "Pat Raymaker".

Patricia Raymaker
Chairperson, NACA

CONTRIBUTORS

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- **Shari Brotman** is Assistant Professor at the McGill School of Social Work. She has worked extensively as an educator, researcher and practitioner in the fields of social gerontology and anti-oppression social work practice. Her primary area of research and writing is related to access to service among marginalized communities. Dr. Brotman is currently the coordinator of the Graduate Certificate in the Interdisciplinary Field of Aging and coordinator of Project Interaction, the Gay, Lesbian, Bisexual and Two-Spirit Initiative, both of the McGill School of Social Work.
- **Jocelyn Charles** is a family physician and an Assistant Professor in the Department of Family and Community Medicine at the University of Toronto. She is also Medical Director of the Cognitive Support Unit in the Long Term and Veterans' Care Directorate at Sunnybrook and Women's College Health Science Centre. Dr. Charles has worked in long term dementia care at Sunnybrook for the past 12 years. She was involved in the design and operational planning for the Dorothy Macham Home, an innovative care and research facility for ten residents with challenging behaviours due to dementia, where she is currently the attending physician. She is also involved in research into the safety risks of cognitively impaired seniors who live alone.
- **David K. Conn** is the Psychiatrist-in-Chief at Baycrest Centre for Geriatric Care and Associate Professor in the Department of Psychiatry, University of Toronto. He is the President of the Canadian Academy of Geriatric Psychiatry and Co-Chair of the Canadian Coalition for Seniors' Mental Health.

Dr. Conn's academic interests include the psychiatric consequences of brain disease in the elderly, nursing home psychiatry and pharmacoepidemiology. He is the co-editor of three textbooks, including "Practical Psychiatry in the Long-Term Care Facility: A Handbook for Staff."

- **Robert Cormier** has recently obtained a Master's degree in Social Work from McGill University. His area of interest focuses mostly on issues of access to health services for marginalized populations. He possesses extensive front-line experience both within the fields of mental health and gerontology. Mr. Cormier is currently employed with Veterans Affairs Canada - Québec Region where he provides training and clinical supervision.
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- **Betty Havens** is a full professor and Senior Scholar in the Department of Community Health Sciences, Faculty of Medicine, University of Manitoba. She is frequently called upon to consult, study and review proposals, projects and manuscripts locally, nationally and internationally that concern aging, home care and long-term care programs. She is a member of the Canadian Institutes of Health Research's Institute of Aging Advisory Board and a

former president of the Canadian Association on Gerontology. She is, however, perhaps best known for her role as the principal investigator of the Aging in Manitoba Longitudinal Study, since 1971.

- **Karen Henderson** is founder of the Caregiver Network and Howtocare.com. Completely changed by her personal caregiving experience, she started the Caregiver Network on the Internet in 1996 and How to Care in 2000. She also launched The Caregiver, a quarterly newsletter and the Personal Care Binder. She co-created and produced the TV/video series Caregiving with June Callwood and *The Complete Aging and Caregiving Resource Guide*. Karen is often asked to speak to consumer and health care organizations about aging and eldercare. She sits on provincial committees for elder abuse and dementia and is also a founding member of two national coalitions to improve the lives of caregivers and end-of-life care for all Canadians.
- **Elizabeth Lockhart** attended the University of British Columbia (B.A.), Simon Fraser University (M.A.) and the University of Regina (Ph.D.). She began her career teaching English at secondary schools in British Columbia. After completing a Ph.D. in Psychology, she worked clinically with a psychogeriatric outreach program in Peterborough, Ontario, as the Regional Manager of Elderly Mental Health Services in the North Region of British Columbia and as a consultant with Continuing Care and the Office for Seniors in the British Colombia (BC) Ministry of Health.
- **Penny MacCourt** is a social worker. She received her Bachelor and Master of Social Work in Manitoba. The majority of her professional practice has been with elderly persons with and without mental health problems, in acute care, long-term care and community settings. She is the Past President of BC Psychogeriatric Association. She is an Interdisciplinary Doctoral candidate in mental health, aging and service delivery. She has received research awards from the Alzheimer society of BC and Canada.

- **Dolores Pushkar** is a Professor of Psychology and a Principal Member of the Centre for Research in Human Development at Concordia University. The majority of her research has been based on field studies examining the effects of naturally occurring variables, such as gender, socioeconomic status and, for the last 23 years, aging. Her research has focused on variables and processes that help to explain the maintenance of cognitive, emotional and social competence, with particular emphasis on psychosocial factors.
- **Bill Ryan** is a social worker and adult educator who teaches at the School of Social Work of McGill University. He founded an organization called Project 10 in Montréal, which has become one of the largest service organizations for gay, lesbian and bisexual youth in Canada. He has taken this model and adapted it as “The Safe Spaces Project” for Health Canada. It is presently being tested in three other cities: Moncton, NB; Halifax, NS; and Kamloops, BC. For the last 10 years he has worked individually with hundreds of gay men and lesbians in psychotherapy. Since 1998 he has been working with the World Health Organization in Eastern Europe. He is the author of many papers, articles and chapters on HIV prevention, care, sexuality, and sexual orientation. He is co-editor of a recent publication entitled *Social Work and HIV: The Canadian experience*.
- **Mary Catherine Tierney** is a Senior Scientist and Director of the Geriatric Research Unit at Sunnybrook and Women’s College Health Sciences Centre, University of Toronto. She is also a clinical psychologist for the Long Term and Veterans’ Care Directorate at Sunnybrook and Associate Professor, Department of Family and Community Medicine, University of Toronto. Her research, which has been published nationally and internationally, focuses on the prediction of Alzheimer’s disease in memory-impaired people, the differentiation of Alzheimer’s disease from other forms of dementia, and the ability of seniors who live alone to function safely in the community. She is currently leading a large randomized clinical trial to examine the effectiveness of estrogen replacement therapy in delaying the onset of Alzheimer’s disease in women with memory impairment.

**POSITIVE MENTAL HEALTH IN AGING:
CHALLENGES AND RESOURCES**

by

Dolores Pushkar and Tannis Arbuckle

**October 2002
National Advisory Council on Aging**

The context of aging

Aging is an astonishingly heterogeneous phenomenon. Contrary to widespread negative stereotypes about aging that are believed even by health care workers and seniors themselves,¹ many people find growing older and becoming free of occupational and major family responsibilities is a time of decreased stress and increased freedom.² But the experience of growing older is greatly influenced by life history, genetic heritage and life context, including age, gender, health, socioeconomic and marital status. Aging reflects the circumstances of people's lives and consequently, we need to appreciate the factors that shape both the risks for and the resilience to the problems linked with aging.

Gender and income are important and related factors in people's lives. Because women usually marry older men, live longer and are less likely to remarry after divorce, more older women will be living alone with reduced social and financial support. In contrast, most men, who typically marry younger women, are more likely to remarry after divorce, and have shorter life expectancies, will grow old with a spouse and will benefit from dual incomes. Most older women have had more unpaid family responsibilities, had fewer years of paid pensionable employment, and received lower salaries than men. Further, many women were employed in jobs that did not provide pensions. As a result, most older women are poorer than older men.

It is well established that growing old is harder for poor people. Poverty goes along with poorer health, more limited activities and shorter life expectancies. As government infrastructure support is cut back, the very old, the poor and especially older women who are both poor and living alone, will be at greatest risk for problems and most in need of help from family and friends.

But there is a brighter picture for future seniors. Those people who will grow old in the near future will be better educated and will have experienced better nutrition, public health and medical care. Further, because more women now have paid employment, more women will grow older with adequate financial resources. And very importantly, as the numbers of older people grow, so does their economic and political clout, influencing both government policy and social attitudes. One

older person alone is isolated; many older people together can become a base for social action.

The following overview of research in the field of aging will provide a baseline for understanding the mental health problems of aging by examining how most seniors maintain positive mental health. The ability to cope with life tasks and adapt to environmental demands in both normal and stressful circumstances is central to maintaining mental health. Such adaptation is necessary throughout life. At all life stages people have limited resources and adaptive capacity, thus, every choice of one path means rejecting another and causes the loss of potential for other developmental paths. Adaptation becomes more difficult in old age because of decreasing psychological, biological, social and economic resources. In addition, the quality of aging is also determined by choices made much earlier in life. Many declines often attributed to old age are due to other factors, which accelerate the loss of function. Obvious factors include illness, trauma, long-term consequences of lifestyle choices and disuse of abilities. Less obvious are life changes that reduce the challenges that enhance functioning, such as dropping responsible roles or using technology to reduce physical effort, e.g., a golf cart.

The limits of healthy aging are unknown, but the achievements of increasing numbers of older people lead us to conclude that the limits are rapidly expanding. Consequently, it is important to understand what causes abilities to decrease in old age and how they can be improved. The first step is to examine how most older people maintain positive mental health and the contexts which help them do so.

Emotional and social functioning

Mentally healthy adults are able to control their emotions so that they generally experience well-being, are not depressed and feel good about themselves. They are also sufficiently resilient to cope with stressful occurrences and after doing so, to return to their previous state of well-being. A person's level of well-being is quite stable across the adult lifespan³ and a large majority of adults at all ages describe themselves as happy.⁴

Individual well-being is strongly determined by personality characteristics, such as emotional temperament and extraversion. The high level of stability of personality traits across the adult life span and their influence on well-being suggest that an earlier history of adjustment problems indicate higher risks for problems later in life,³ especially when combined with factors such as poor health.

Well-being is also predicted by life contexts, such as socioeconomic factors and health. Being married also is linked with well-being, primarily for men. The Ageing and Independence Study found that lower stress levels, better health, greater support from family and friends, higher education, greater feelings of security and safety in the home all significantly contributed to well-being for older Canadians. But such factors usually have less impact on well-being than do personality traits.

For most older people, aging brings the effects of negative stereotypes, loss of important employment and family roles, increasing health problems, and shorter life expectancy. Nevertheless, the vast majority of seniors describe themselves as happy or at least as happy as they were when younger.⁵ They achieve this state by developing the skills that help them retain their satisfaction with life and positive sense of self in the long, slow process of aging. These skills include maintaining central values, roles, activities and relationships,⁶ modifying aspirations, being flexible about goals and in solving problems, and being able to anticipate and to control emotional responses to situations.

Older people generally accept negative age stereotypes as applying to others but not to themselves. Most people seem to regard themselves as exceptional. It is also likely that older people do not apply these negative stereotypes to themselves because they are not accurate descriptions of themselves. Many older adults feel younger than their age, do not consider themselves to be “old” and maintain many middle-aged lifestyles.

Increasing discrepancies between what one wants to do and what one can do, however, make it difficult to maintain younger habits and goals. Research has shown that a downward shift of aspirations occurs at older ages to reduce such discrepancies. For example, older people who pride themselves on their skiing prowess might decide that speed is not important as long as they are still able to ski, unlike most of their age-peers. This serves to maintain a continuing and positive

sense of self. Flexibility in re-evaluating goals and being able to accommodate personal preferences to situational limits is an important skill in maintaining life satisfaction that becomes easier with age.⁷

How people of different ages react to stress has also been examined.⁸ Older people are less likely to try to change situations to make them better and more likely to change the way they think and feel about the situations, such as seeing the bright side of difficulties. When there is limited, if any, control over difficult events, such as loss of family, friends, and declining income, changing one's view about events and finding ways to adjust to them is the healthiest way to increase well-being.

Other research suggests that emotional control becomes more effective, with older people experiencing fewer negative emotions. Older people appear to regulate their emotions more effectively than do younger people, selectively enhancing positive emotions and dampening negative emotions. Older people are also more likely to avoid situations that cause negative emotions.⁹ This strategy of preventing negative emotions from appearing contrasts with attempts to control emotions after negative reactions have begun, as more commonly done by younger people.

As is generally true across the lifespan, most older persons function best within a supportive social context. There is little research on the social skills of older persons, but it appears that older and younger adults generally do not differ. When problems in social skills develop in older people, they appear to be related to aging disabilities.

Many research findings show that having family members and friends available to provide emotional support, instrumental help, and companionship is important for well-being and health.¹⁰ Recent examinations of social support and age emphasize the active role of individuals as they choose among various people according to their needs at different ages. Selectively reducing social interaction begins early in adulthood. Emotional closeness with family, close friends and relatives increases while people who are more peripheral or who have histories of creating unpleasant situations are phased out throughout the adult years. By late adulthood, social networks are emotionally condensed, characterized by high emotional closeness with fewer people.⁹ Thus, the smaller number of social ties

reported by most people in late life is partly due to the elimination of peripheral or unsatisfactory relationships.

These condensed social networks may be efficient in increasing well-being, but their reduced numbers create vulnerability. Attrition can lead to the loss of intimate relationships that can never be replaced. It is not surprising, therefore, that research indicates that compared to younger people, older people spend significantly more time alone. Although loneliness does not appear to be a particular problem for younger old people, at the upper age ranges approximately half of people over age 80 have reported feeling lonely.¹¹

Family members are the chief source of regular contact and help for older persons. However, contact with friends is vital for well-being and may be more important for morale than contact with family.¹² Contact with friends is usually voluntary, engaged in for its own intrinsic rewards. Contact with family members also provides intrinsic rewards, but frequently involves seniors receiving help from younger relatives. Consequently, contact with family members can reinforce feelings of dependency and loss of autonomy for older people. The ability to maintain well-being is dependent upon personal and social assets, which change with age. Older people who have more favourable personality traits, social support, economic, sensory, motor and cognitive abilities are able to engage in a greater variety of activities and more successfully meet personal goals. But with increasing age, there is a downward shift in general functioning. Consequently, at the oldest ages, there are more people who have poorer economic resources and slower and less efficient cognitive functioning. These individuals are also more likely to have reduced social support and increasing health problems leaving them vulnerable to loneliness and depression. This is particularly true for the oldest women. Findings suggest that the adaptive techniques that allow older people to maintain high levels of well-being become less effective in extreme old age, leaving at greatest risk for problems the very old, and among these elders, most frequently women who live alone on low levels of income.

Cognitive functioning

What happens to mental abilities as people age? There are normative changes in the eyes, ears, and the brain itself that affect the ability to perceive, think, and remember, but any cataclysmic decline in mental ability in old age is the result of disease processes, not normal aging.

The normative changes with age in cognitive abilities are both positive and negative. Knowledge grows over adulthood and provides a basis for increasing wisdom in managing problems of everyday life. On the negative side there is a decline with age in the speed of mental processing¹³ and a decrease in the ability to inhibit irrelevant information.¹⁴ Cognitive slowing impedes the ability to perform multiple tasks at the same time, such as conversing with new acquaintances and actually remembering what they said, e.g., their names. Less efficient inhibitory processes account for “senior moments.” These momentary lapses of memory are due to irrelevant bits of information being activated during the memory search and temporarily preventing access to the desired information. Such memory problems occur at any age, but with cognitive slowing and decreased inhibitory control due to aging, they become more troublesome.

The most interesting aspect of cognitive aging is the existence of large individual differences in how well cognitive abilities are maintained. The “use it or lose it” explanation of individual differences in cognitive aging suggests that people who engage in intellectually stimulating activities will better maintain their competence. A study of intellectual change over 40 years in Canadian World War II veterans showed that an active, engaged adult lifestyle helped explain maintenance of intellectual functioning.^{15, 16} Exciting new findings suggest that participation in stimulating activities may even reduce the risk of developing Alzheimer’s disease.¹⁷ To date, researchers have not established which activities are particularly helpful in maintaining cognitive competence. Both social and intellectual stimulation appear important. Physical activities also likely contribute to cognitive maintenance. Physical fitness facilitates intellectual and social engagement and may also directly improve cognitive functioning through increased cerebral oxygen access.

To the extent that older individuals do experience normal age-related declines in cognitive speed and inhibitory control, they typically use adaptive strategies to minimize any real impact of these changes on their everyday life. Older adults compensate for memory difficulties by writing down appointments, using pill box reminders for taking their medications and so on. To compensate for cognitive slowing, they reduce the information load by, for example, avoiding driving under challenging conditions of traffic flow and weather. Such strategies are part of the life management skills that people build up over their lifetime and that serve them well in maintaining their independence and well-being in their senior years.

Conclusion

As this research summary indicates, there has been a shift from viewing older individuals as passively undergoing inevitable ravages of age to emphasizing their active adaptation of themselves and their environments. If the term “old” means age 65 and over, it encompasses great diversity. Two relatively distinct older adult populations exist. The first is composed of the majority of older persons, particularly younger old people, who lead generally independent, healthy, and satisfying lives in their own homes. The second, which is smaller in size but increases as people age, is composed of the frail seniors who have disabilities, require increasing assistance from family, friends, the helping professions and perhaps ultimately, institutional settings.

It is important that older people and practitioners who work with them avoid regarding pathology as the inevitable norm. Lack of awareness of the range of normal functioning in seniors can help contribute to the over-diagnosis of pathology. This can lead to a lack of proper response, since a symptom may be believed to be inevitable. Alternatively, over-diagnosis can also lead to premature interventions, for example prescribing tranquilizers, which can reduce the ability to develop more effective ways of coping.

It has been argued that we are moving towards an age-irrelevant society,¹⁸ in which people are free of age constraints and are restricted only by their individual circumstances. This change in attitude is usually regarded as praiseworthy in that stereotyped age stigmas are likely to disappear. However, one danger of such an approach is that it may lead to a failure to provide required services for frail

seniors. Further, the concept of an age-irrelevant society is based on the assumption that the required functioning of adults is the same at all ages. Consider the popular term, successful aging. Examples of successful aging often illustrate older people with exceptional achievements for their age. However, just as we do not demand exceptional performance by children and middle-aged adults to consider them successful, similarly we should not require exceptional performance by seniors. Successful aging should not mean acting like a younger person. Success is self-defined and will take a multitude of different forms. The term successful aging should convey the message that, despite experiencing the disadvantages of age, older people enjoy the benefits of growing older, knowing that with help they can cope with their problems, and maintain a satisfying and meaningful way of living for this stage of life. Fortunately, the research indicates that most older people are able to do this.

Endnotes

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**AN OVERVIEW OF COMMON
MENTAL DISORDERS AMONG SENIORS**

by

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Defining mental health and mental disorder

In a 1988 publication entitled *Mental Health for Canadians: Striking a Balance*, Health and Welfare Canada developed a broad definition of mental health: “the capacity of the individual, the group and the environment to interact with one another in ways that promote subjective well-being, the optimal development and use of mental abilities (cognitive, affective and relational), the achievement of individual and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality.”¹ A mental disorder may thus be defined as a recognized, medically diagnosable illness that results in a significant impairment of the individual’s cognitive, affective or relational abilities. Mental disorders generally result from biological, developmental and/or psychosocial factors which can be managed via prevention, diagnosis, treatment and rehabilitation. A biopsychosocial approach to the formulation and care of individuals with mental disorders is critically important. In North America the diagnostic system for mental disorders is entitled the Diagnostic and Statistical Manual, IV or “DSM-IV.”²

Epidemiology of mental disorders among seniors

Most mental disorders are generally no more prevalent among seniors than other age groups, the exception being dementia and delirium. The prevalence of mental disorders among seniors as a group varies considerably depending on where they live. The prevalence of clinical depression among community-dwelling seniors is between 2% and 4%. However, if all patients with depressive symptoms are included, the rate rises to between 10% and 15%. A study of mental disorders among community living seniors in Edmonton reported that 11.2% were experiencing some form of depression.³ The prevalence rates for females (14.1%) was almost twice the rate reported for males (7.3%). Prevalence rates for depression are much higher among long-term care residents and individuals with chronic medical conditions. The six-month prevalence rate for all anxiety disorders in individuals over age 65 is reported to be 19.7%,⁴ with the most common form of anxiety being phobic disorder.

Valuable data regarding the prevalence of dementia in Canada have been obtained from the Canadian Study of Health and Aging which evaluated over 10,000 subjects in five regions of Canada.⁵ Approximately 250,000 Canadians representing 8% of the population age 65 and over met the criteria for dementia. Among those aged 85 and over, the prevalence of dementia rose to 34.5%. Approximately 60% of individuals with dementia were considered to have Alzheimer's disease and almost 20%, vascular dementia. It was estimated that the number of Canadians with dementia will rise to 592,000 by 2021. It is important to note that behavioural and psychological symptoms of dementia (BPSD) occur frequently.^{6,7} These problems include physical and verbal aggression, anger, wandering, insomnia, depression, delusions and hallucinations.

The diagnostic assessment

The assessment of a senior with mental health problems begins with the history of the person. Many individuals can give a clear account of their problem, but in other cases it is critical to obtain additional information from family or other caregivers. The complete history includes the following categories: chief complaint, history of presenting illness, past psychiatric history, past medical history, family history, personal history, current medications, drug and alcohol history and a history of functional status, in particular, the activities of daily living (ADLs). The ADLs include the basic functions, as well as more complex tasks which are referred to as instrumental activities of daily living (IADLs). In addition to the history, it is important to assess the person's mental status which includes the following components: behavioural observations, mood and affect, thinking processes, perception and cognition. The major components of cognitive function include: attention and concentration, language, memory, abstraction, visuo-spatial function, praxis (ability to carry out learned movements), insight and judgement. The most commonly used screening instrument to assess cognition is the Folstein Mini Mental State Examination, which allows clinicians to determine quickly whether there might be a significant problem.⁸ This instrument is a 30-item test where scores of 24 or less generally indicate a significant problem. It is important to note that such instruments are only used for screening and cannot be used to make a diagnosis. A full evaluation also requires a physical/neurological examination because of the frequent coexistence of medical and mental disorders. Investigations often include blood tests and brain scans.

Common mental disorders among seniors

Depression

The term depression generally refers to a feeling of sadness or low mood. There are a number of different disorders which are characterized by depressed mood. If an individual has experienced a period of significant depression, it is important to consider the different diagnostic possibilities. A person with severe depression is generally diagnosed as having a Major Depression, sometimes referred to as clinical depression. However, individuals with less severe depression may have an adjustment disorder with depression, which refers to a change in mood occurring as a reaction to a particular life event. Some people suffer from a chronic low-grade depression which may last for years, which is referred to as dysthymic disorder. If the depression appears to be clearly related to a physical illness or a medication, the diagnosis is specified as such, e.g., depression due to stroke. When there is a history of episodes of high mood (hypomania or mania), then a diagnosis of bipolar disorder is made. If the person has recently become bereaved, he or she may simply be suffering from uncomplicated bereavement. However, it should be noted that if the symptoms of grief become chronic, the possibility of clinical depression must be considered. It is also possible that a person experiencing depressed mood may be suffering from another non-mood related mental disorder, e.g., an anxiety disorder, personality disorder or alcohol/drug abuse or dependency.

As depression in seniors is often more difficult to recognize than in younger individuals, and seniors are less likely to spontaneously describe it, clinicians must be more proactive in the detection of depression symptoms. Studies suggest that the consequences of unrecognized and untreated depression in seniors may include excessive use of health care services, increased length of stay during hospitalization, decreased treatment compliance and increased morbidity and mortality, related to underlying medical illness and from suicide. Health care professionals should always be vigilant for depressive symptoms in any patient who appears sad or withdrawn, has unexplained physical complaints or is simply failing to thrive. In individuals whose pain seems inconsistent with physical findings or appears to be excessive in relation to the underlying disorder, the possibility of depression should not be ruled out. The DSM-IV criteria for Major Depression are listed in Table 1.

Individuals who have suffered recent losses are at increased risk of developing depression. In seniors these losses may include bereavement, loss of health or loss of their role in society. Those living alone are particularly vulnerable and other risk factors include being female, unmarried or widowed and having coexisting physical illness. Of particular concern is the rate of completed suicide which is particularly high in seniors, especially white males. Therefore, when depression is suspected, it is very important for health professionals to ask about suicidal thoughts. One recent study suggested that 66% of those who had completed suicide had visited a general practitioner in the month prior to their death.⁹ Screening instruments such as the Geriatric Depression Scale can be helpful in detecting the possible presence of depression.¹⁰

Mania

Bipolar mood disorder is usually characterized by episodes of both depression and of high or elevated mood. When these episodes of high mood are mild, they are referred to as hypomanic episodes and, when severe, they are termed manic episodes. During a manic episode the mood is generally elevated, or expansive, although in some cases it is irritable. The individual often demonstrates grandiose thinking, is very talkative and has reduced need for sleep. Flight of ideas, characterized by thinking that is difficult to follow, with one thought jumping to the next, is often present. The person is often distractible, impulsive and drawn towards pleasurable activities that may be dangerous or illegal. Several medical illnesses and medications are associated with the development of mania.

Psychotic disorders

Psychotic disorders can be defined as those resulting in gross impairment of contact with reality or simply disorders in which delusions or hallucinations are present. It is important to note that in seniors psychotic symptoms are frequently associated with dementia or delirium and that a number of physical conditions can give rise to psychotic symptoms. Psychotic symptoms can also occur in severe mood disorders such as depression or mania. In younger persons the most common psychotic illness is schizophrenia. This disorder is characterized by symptoms such as delusions and hallucinations as well as social withdrawal and apathy. Most patients with schizophrenia develop delusions, which are persecutory in nature and

may be quite bizarre. Auditory hallucinations are also very common. Some individuals may develop a schizophrenia-like illness late in life. Social withdrawal is common, with elaborate or bizarre delusions. Sensory impairment, particularly diminished hearing, is often associated with this disorder. Other individuals may develop a delusional disorder which is characterized by the presence of persistent, non-bizarre delusions (i.e., involving situations that can occur in real life, such as being followed, poisoned, infected, loved at a distance, deceived by a spouse or lover, or having a disease).

Anxiety disorders

Generalized anxiety disorder (GAD) is characterized by excessive worry, often about insignificant matters. The anxiety and worry are intense and out of proportion to the situation. Common symptoms include restlessness or feeling on edge, fatigue, difficulty concentrating, irritability, muscle tension and sleep disturbance. Other somatic symptoms include dry mouth, sweating, diarrhea, urinary frequency, headache, dizziness, palpitations, tremor and a subjective sense of shortness of breath. Panic disorder is characterized by recurrent unexpected panic attacks. These panic attacks may be associated with particular situations and, therefore, avoidance of those situations is common. Some individuals become phobic and avoid crowds as well as situations from which they feel it is difficult to escape. This is called agoraphobia and may result in severe restriction of activities. These individuals may become housebound and may need companions in order to perform everyday activities. Post-traumatic stress disorder (PTSD) follows exposure to an event which involves death, serious injury or threat to the physical integrity of the person or others, and which evokes a response of intense fear, helplessness or horror. This disorder can persist throughout life and some seniors who have experienced military combat, concentration camps or violent/sexual assault may experience persisting symptoms. These include recurring images of the event, a tendency to avoid associated stimuli and the development of persistent symptoms of increased arousal, e.g., insomnia or hypervigilance. They may experience dreams, flashbacks and intense distress when exposed to reminders of the event. Obsessive compulsive disorder (OCD) is characterized by obsessive thoughts or compulsive behaviours which include excessive washing, cleaning, counting and checking.

Dementia

The dementias are a group of disorders characterized by cognitive and functional impairment. They are generally persistent and progressive illnesses. Individuals with dementia usually demonstrate some memory impairment, although this may not occur in the early stages of the illness. According to the DSM-IV criteria for dementia, there should be evidence of memory impairment and difficulty in at least one other cognitive area (see Table 2). The diagnosis of dementia is primarily clinical and is made on the basis of the history and the clinical examination. When dementia is suspected, various laboratory investigations are carried out to rule out potentially reversible causes such as a vitamin B-12 deficiency and thyroid disease. Some patients with severe depression can present with significant cognitive impairment, which is sometimes reversible with the treatment of the depression. This disorder is referred to as the dementia syndrome of depression or pseudo-dementia. In addition to memory disturbance many patients with dementia demonstrate behavioural problems such as agitation, aggression, wandering, repetitive or bizarre behaviours, hallucinations, delusions, shouting, disinhibited behaviours, sleep disturbance and sexually inappropriate behaviour. The common causes of dementia are listed in Table 3. The most common form of dementia is believed to be Alzheimer's disease followed by vascular dementia. There is now growing evidence that a combination of the two diseases (known as mixed dementia) may be more frequent than either disease alone. Although at this time there is no specific laboratory test or imaging technique that can result in a definitive diagnosis of Alzheimer's disease, it is useful to obtain computerized tomography (CT) or magnetic resonance imaging (MRI) brain scans to ensure that there is no underlying brain disease, such as a stroke or tumour, which may be causing the symptoms.

Delirium

Delirium is a generally reversible condition which occurs as a result of an acute disturbance of brain function. It is generally precipitated by a physical illness or drugs. Individuals with delirium generally display behavioural changes such as extreme agitation or withdrawal and drowsiness to the point of stupor. Delirium is most frequently seen in the general hospital setting, in which there are many patients with acute medical illnesses. Post-operative patients are especially vulnerable. The

diagnostic criteria for delirium are listed in Table 4. Patients are generally disoriented and have impaired recent memory and there is an inability to focus, maintain and shift attention. Speech may become rambling and incoherent and patients have reversals of their sleep/wake cycle, generally sleeping excessively during the day, while being unable to sleep at night. They sometimes have hallucinations, most commonly visual in nature. Although delirium can be seen at any age, it is most common in seniors, and individuals with underlying dementia are at higher risk for its development. Provided that the underlying cause is treated, the vast majority of individuals make a complete recovery from an episode of delirium, although in seniors, recovery may be slow and it may take weeks to months before the person returns to normal.

Management of mental disorders in seniors

Fundamental principles need to underlie the delivery of mental health services for seniors: comprehensiveness, defining the target population, community outreach, availability and flexibility, and support for caregivers.¹¹ For those with serious illness, optimal services are generally provided by a multidisciplinary group of mental healthcare workers. Community outreach services are a cornerstone of geriatric care as many seniors are housebound and it is essential to be able to provide care for people in their own homes. There is often a need to improve coordination between hospital-based services and community-based services, which generally consist of a large number of health and social agencies.

Management should reflect the biopsychosocial approach which takes into account a variety of treatment options. It is very important to involve family and other caregivers, when available, and to provide education with regard to mental disorders and their management. Many seniors can benefit from psychotherapy. Common approaches include supportive therapy, reminiscence or life-review therapy, cognitive therapy and interpersonal therapy. Behaviour management strategies can be particularly helpful in the management of challenging behaviours, associated with cognitive impairment. This approach requires attention to cognitive deficits, environmental factors that trigger or maintain the challenging behaviours and, in an institutional setting, an understanding of staff attitudes, perceptions and expectations.

A variety of groups of psychotropic medications are available. Clinicians need to be aware that seniors are more vulnerable to side effects from medications, that many factors can affect drug metabolism in the elderly, and that it is necessary to establish the relative indications and contraindications for medication use in each individual. There should be a specific diagnosis as well as target symptoms which can be used to monitor the effectiveness of treatment. The five major groups of psychotropic medications are: antidepressants, mood stabilizers, minor tranquilizers, antipsychotics and cholinesterase inhibitors. Antidepressants are primarily used to treat depression and anxiety disorders. Mood stabilizers are used to treat mood and behaviour disturbances. Minor tranquilizers are helpful in the treatment of anxiety symptoms and insomnia, preferably for short periods of time. Antipsychotic medications are used to treat psychotic disorders and behaviour problems associated with the dementias. Finally, in recent years, medications have become available for the treatment of Alzheimer's disease and other dementias. These medications are called cholinesterase inhibitors and although they do not cure the underlying illness, they appear to slow down the rate of progression. It is likely that in the years ahead numerous agents will become available to modify further the progression of these disorders.

Conclusion

As the proportion of seniors in the population grows rapidly, the care of those with mental health problems will become an important priority for those planning health care and social services. Seniors are particularly vulnerable to the development of certain mental disorders, especially those related to degenerative brain disorders, e.g., Alzheimer's disease. Seniors with chronic medical problems and those living in institutions are at high risk of developing depression and other mental disorders. A greater emphasis on prevention should occur in the future, as we learn more about risk-reducing approaches.

In recent years, through the discovery of new pharmacological agents, the development of psychosocial therapies and the implementation of innovative service delivery systems, the care of seniors with mental illness is gradually improving. Hopefully, adequate resources will be available to ensure that seniors will receive optimal assessment and treatment in the years ahead.

Table 1

DSM-IV DIAGNOSIS OF MAJOR DEPRESSION

At least five (5) of the following symptoms* have been present nearly every day, for most of the day, during the same two-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest in pleasure:

1. Depressed mood, either subjective or reported by others
2. Markedly diminished interest or pleasure
3. Significant change in weight or appetite
4. Insomnia or hypersomnia
5. Psychomotor agitation or retardation
6. Fatigue or loss of energy
7. Feelings of worthlessness or excess of inappropriate guilt
8. Diminished ability to think or concentrate or indecisiveness
9. Recurrent thoughts of death or suicidal ideation

* *Symptoms cause significant distress or impairment in daily activities, social life, or other important areas of functioning.*

* *Symptoms are not due to the direct effects of a substance (e.g., drugs of abuse or medication) or a general medical condition.*

(Adapted from DSM-IV, American Psychiatric Association, 1994.)

Table 2

DIAGNOSTIC CRITERIA FOR DEMENTIA	
A-	<p>1) Memory impairment, AND</p> <p>2) At least one of the following:</p> <ul style="list-style-type: none"> i) disorder of language (aphasia) ii) inability to carry out motor activities (apraxia) iii) inability to recognize objects (agnosia) iv) impairment of abstract thinking, judgement, planning (executive functioning)
B-	The disturbance in A- 1) and 2) significantly interferes with work or usual social activities or relationships with others, and represents a decline from a previously higher level of functioning.

(Adapted from DSM-IV, American Psychiatric Association, 1994.)

Table 3

CAUSES OF DEMENTIA	
<ul style="list-style-type: none"> • Alzheimer's disease • Vascular dementia • Dementia with Lewy Bodies • Alcoholic and other toxic dementias • Frontotemporal dementia (including Pick's disease) • Normal pressure hydrocephalus • Dementias secondary to metabolic disturbances: <ul style="list-style-type: none"> - Thyroid disease - Vitamin B₁₂ deficiency 	<ul style="list-style-type: none"> • Dementia with other neurologic illness: <ul style="list-style-type: none"> - Parkinson disease - Huntington disease - Wilson disease - Multiple sclerosis • Infectious dementias: <ul style="list-style-type: none"> - Syphilis - Creutzfeldt-Jakob disease • Dementia from head trauma • Dementia from brain tumours • Dementia syndrome of depression

(Source: Herrmann, N. and R. van Reekum. In D. K. Conn et al. Practical Psychiatry in the Long-Term Care Facility: A Handbook for Staff. Seattle, US: Hogrefe and Huber, 2001.)

Table 4

DIAGNOSTIC CRITERIA FOR DELIRIUM

- Disturbance of consciousness (i.e., reduced clarity of awareness of the environment) with reduced ability to focus, sustain, or shift attention.
- A change in condition (such as memory deficit, disorientation, language disturbance) or the development of a perceptual disturbance that is not better accounted for by a pre-existing, established, or evolving dementia.
- The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day.
- There is evidence from the history, physical examination, or laboratory findings that the disturbance is caused by the direct physiological consequences of a general medical condition.

(Adapted from DSM-IV, American Psychiatric Association, 1994.)

Endnotes

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**SOCIAL ISOLATION AND
SOCIAL LONELINESS**

by

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Social isolation and social loneliness: definitions

Social isolation and social loneliness are situations that tend to increase as people age, and as family and friend-networks become smaller. Social contacts generally decrease after retirement, and may continue to decline with the deaths of family members and friends, and changes in residence following widowhood, mobility difficulties, and ill health.

Social isolation is usually measured by the number of personal contacts, and is defined as being separated from one's environment to the point of having few satisfying and rewarding relationships.¹ It specifically refers to a small number of overall contacts with a broad array of people including relatives, friends, neighbours, and co-workers. Social isolation is sometimes referred to as solitude, or aloneness, and can result from personal choice; that is, some individuals find many benefits in spending time alone to read, watch TV, or to work on hobbies. Such people might not feel the need for as much company as others. They might therefore be defined as isolated, but at the same time may not be lonely.

Social loneliness, on the other hand, is one's feeling of dissatisfaction with social contacts in terms of quantity of contacts, quality of the relationships, or both. Defined this way, social loneliness is not a personal choice; that is, while you might choose not to spend time with others, you do not generally choose to feel badly about the contacts you are lacking. In other words, social isolation is an objective measure of social contact, whereas social loneliness reflects negative subjective feelings about the quality of contacts.

Just as social isolation can occur without the presence of loneliness, so can social loneliness occur even among those who appear outwardly to have many contacts. For instance, loneliness might be indicated when someone says she misses a spouse or a close friend who has died, or feels that close friends or relatives are not often available for social activities or emotional support. This may result even though the individual participates in activities that result in many social contacts.

As a social concept, an expression of loneliness highlights the importance of social perceptions and evaluations of personal relationships. In particular, loneliness is defined by those situations where the number of relationships is smaller than

expected, or the quality of the existing relationships is less than desired.² Such situations might be described according to the theory of mental incongruity. In this view, feelings of loneliness are caused by a discrepancy between the relationship one desires and the ability to achieve or maintain the amount and type of contact that one expects.³ A typical example of mental incongruity would be the expectation of maintaining a lifelong relationship, but one's partner dies. "In accordance with the theory, older men and women with a partner are found to be more vulnerable to loneliness when they have either a high partner standard [expectation] or a low single-hood standard [expectation], but see few opportunities to change their situation."⁴ In other words, personal and societal expectations favouring marriage over remaining unmarried may result in a greater risk of loneliness among those who are no longer married because of the death of their spouse.

The link between isolation and loneliness remains blurred, but many researchers agree that a reduction in social contacts can precipitate an expression of loneliness. For example, a 1998 study by Ryan⁵ on hospitalized seniors showed that any change leading to a decrease in social contact with significant others, such as retirement, the development of an illness, the death of family members or friends or through relocation of one's residence, resulted in increased levels of loneliness. In Canada, the Aging in Manitoba Study also found a significant association between contacts and loneliness, with those having the fewest contacts expressing the highest levels of loneliness.⁶

Prevalence of loneliness among seniors

As can be expected, rates of loneliness depend on the particular population studied, and on the measure used. Typical measurement scales are the UCLA Loneliness Questionnaire,⁷ and the Loneliness Scale developed in the Netherlands.² Perlman⁸ has traced the literature on loneliness back to T. L. Stoddard's 1932 volume entitled *Lonely America*, but suggests that loneliness was largely ignored as an area of research interest until the 1970s. As early as 1975, it was reported that 12% to 40% of older Americans experienced loneliness.⁹ In the 1980s Delisle¹ reviewed studies of loneliness from various countries and found rates varying from under 20% to over 60%, similar to his findings in a Quebec study where loneliness ranged from among 20% to 54% of the older population. A more recent US report stated loneliness was experienced by two-thirds of the study sample,¹⁰ while a

European study reported a range from 12% to 23% of older people, depending on age.¹¹ One researcher cites a British report stating that 90% of older people surveyed felt that loneliness was a problem related to aging, but only 32% said it was a problem for them personally.¹² Some studies have found that loneliness increases with age, being strongest among the oldest age groups; some have found that loneliness decreases with advancing age, and still others have found no association at all between age and loneliness.^{13, 14}

The Aging in Manitoba Study research on lonelinessⁱ found that four out of five participants aged 72 and over expressed some degree of loneliness, with 38% expressing low levels of loneliness, and 45% expressing high levels of loneliness.⁶ As well, using the Life Space Index,^{15, ii} 85% of the sample was defined as socially isolated due to a low number of regular social contacts. Loneliness in this study was closely related to age. Specifically, the loneliest members of the sample were more likely to be 90 years of age or older, and those who expressed no loneliness were more likely to be between 72 and 84 years old.

Underlying factors related to loneliness

Widowhood

It is generally accepted that loneliness is more prevalent among those who are widowed.¹² Lopata¹⁶ found that loneliness was one of the major problems of American widows, and Korpekyj-Cox¹⁷ found that the widowed reported higher levels of loneliness than married individuals, regardless of gender or presence of adult children.

Other studies have indicated that those individuals who had recently experienced the death of a spouse had the highest levels of loneliness and those who lived with a partner, husband or wife expressed the lowest levels of

i The Aging in Manitoba Study used a combined measure of loneliness, including responses on the Loneliness Index (de Jong-Gierveld and van Tilburg, 1990), and two single-item measures of loneliness from the NESTOR studies (Havens and Hall, 2001; Hall and Havens, 1999).

ii The Life Space Index is a weighted count of the number and frequency of times in a month that an individual has contact with relatives, friends, neighbours, co-workers, and others such as a regular bus driver or salesperson.

loneliness.^{11, 18} Divorced individuals living alone have also been found to be more lonely than those who were married and living with a spouse.¹⁷ In addition, Woodward and Queen¹⁹ found that loneliness following widowhood was intensified by the length of the marriage, with those married 50 or more years being the most likely to experience loneliness following the death of their spouse. The length of widowhood also appears to be a factor, as those widowed for five or fewer years were found to be more lonely than those widowed for more than five years.

Living arrangements

Regardless of the influence of widowhood, older people who live with a partner or spouse are generally less lonely than those who live alone.⁴ Those who are without a spouse but who live with or near their children have been found to experience greater well-being and lower levels of loneliness in some studies, but other studies found no connection between interaction with children and the experience of loneliness.¹⁴ In fact, Holmen and colleagues¹¹ found that those living with their children experienced the highest levels of loneliness, followed by those residing with a brother or sister.

Hicks²⁰ feels the experience of living in a nursing home is relevant to the experience of social isolation and loneliness among older people. In this study, the lack of intimate relationships, increased dependency, and loss (i.e., friends, home, previous lifestyle, independence and self-identity) were all found to increase the level of loneliness experienced among older people in nursing homes. The author concluded that such factors lead to declining health, increased social isolation, and feelings of sadness and hopelessness.

On the other hand, Andersson²¹ also found that older Swedish people who were socially isolated, who expressed higher levels of loneliness, and who were experiencing declining health were more likely to move to nursing homes or seniors' residences. This finding was confirmed by Russell and Cutrona in 1997,²² who found that higher levels of loneliness among rural Americans increased the likelihood of admission to nursing homes, regardless of age and physical or mental health status. These researchers suggest that moves to nursing homes may be sought as a means to enhance social participation and thereby delay further declines in health.

It remains unclear, however, whether moves to nursing homes are beneficial or detrimental regarding isolation and loneliness. For example, Hall and Havens²³ found there was a public perception that nursing homes may indeed be an isolating environment due to the limited, rather than expanded, opportunity for meaningful social interaction with others. While there may be lots of people in the immediate environment, many residents may be virtually immobile in their own rooms or lack opportunities for satisfying interactions with others. It was also suggested that family and friends may be less likely to visit a nursing home if they feel the environment is unwelcome, or when communication is difficult because of hearing, speech or cognition problems.

Gender

Most researchers have found that women are more likely than men to express loneliness,^{11, 24} but some research has found no link between gender and loneliness.²⁵ Hall and Havens²³ found gender to be a significant predictor of social isolation, but not of loneliness. Women were found to be especially disadvantaged because they are more likely to be widowed and to live alone. Women's advantage over men in life expectancy means that they are more likely to outlive their spouse, other relatives and friends, to live alone, and to experience chronic health problems which limit social interaction.

However, men may have a harder time coping with the loss of their spouse, as it has been suggested they are often less prepared than women for such an event and are less likely to confide in others regarding their grief.²⁶ Women often have a larger social support system than men and more close confidants to help with emotional stresses, including the grief experienced after the loss of a spouse. Typically, men have fewer intimate contacts than women, and have less contact with children, grandchildren and other extended family members.^{18, 26}

The relationship between social isolation, social loneliness and health

Social isolation and social loneliness have consistently been found to be associated with health.^{5, 14, 27, 28} Social isolation and loneliness negatively influence health; and, conversely, declining health status may also lead to increased social isolation and accompanying feelings of loneliness. Perceived loneliness has been

found to be one of the strongest predictors of health status among institutionalized seniors,²⁹ and numerous studies have demonstrated that health is related to the emotional well-being of people in their later years.^{30, 31} A greater use of health care services, such as physician visits and prescription medications, have also been found to be related to higher levels of loneliness.^{22, 27} In addition, self-rated health is related to feelings of loneliness, in that there appears to be a relationship between higher levels of loneliness and lower self-ratings of health.^{6, 11, 23}

Forbes¹² reports that older people suffering from disabilities or chronic conditions such as mobility restrictions, hearing, or vision problems, are more likely to feel lonely, suggesting that these conditions may contribute to isolation because they tend to hamper adequate socialization. Loneliness has also been found to be associated with conditions such as diabetes, coronary heart disease, arteriosclerosis, peptic ulcer, respiratory problems, headache, low back pain, abdominal pain.³²

Perceptions of personal relationships are found to affect feelings of physical health, as well as actual physical health.^{11, 14} One interpretation might be that older people who do not experience loneliness have a more positive view of their personal relationships, have accepted aging and the accompanying changes, and therefore may express a more positive subjective rating of their health.³³

It has been suggested that other factors mediate the relationship among isolation, loneliness, and health. For example, loneliness may predispose older people to the development or worsening of health problems, either directly or indirectly, through other conditions such as depression, or may have a negative effect on the immune system, leading to a variety of health problems.²² Research has also found that individuals experiencing health problems coupled with high anxiety tend to express higher degrees of loneliness and isolation.^{3, 34}

Although the research to date has consistently demonstrated a strong association among social isolation, loneliness and health, the direction of this link remains unclear.⁵ Specifically, do loneliness and/or social isolation precipitate health problems, or do health problems precipitate loneliness and isolation? Some researchers feel that loneliness may result from less contact with others due to ill health,^{14, 35} while others have suggested that loneliness and limited social contact precede ill health.^{36, 37, 38}

Russell and colleagues²² have defined five possible scenarios regarding the association between loneliness and health. The first two suggest that loneliness is a cause, in that loneliness might precede a decline in mental health, or precede a decline in physical health. The last three suggest that loneliness is a result of poor health, in terms of increased chronic conditions, lack of a significant caregiver, or lack of social contacts perceived to be important to the individual. For instance, it is possible that an older individual with health problems may be unable or unwilling to engage in social activities with others, thus leading to social isolation and accompanying feeling of social loneliness. On the other hand, it is also possible that older individuals who are isolated may be less active, have poor nutrition and decreased mental stimulation, all situations which might further the development of health problems.²³

The population health framework offers insight into the association among isolation, loneliness and health.^{39, 40} This perspective views social isolation and social loneliness as determinants of health status. Specifically, isolation and loneliness have the potential to influence the health and well-being of older people, their access to health care, and the effectiveness and outcomes of the health care received. This view provides a broad definition of health including social, emotional, cultural, spiritual and physical factors, and also acknowledges the sociopolitical and economic circumstances of older people.

Strategies to address social isolation and loneliness for older people

A particular strength of the Aging in Manitoba investigation of isolation and loneliness was the participatory nature of the study.²³ The researchers partnered with five local groups interested in seniors' issues. These organizations helped the researchers to arrange and conduct a series of public meetings to develop recommendations for creative and enduring ways to address situations of loneliness among older people. The recommendations were focused at three levels: individuals, community groups and agencies, and program planners and policy makers.

It was suggested that individuals keep in regular contact with older family members, friends and neighbours, and ensure that older people feel needed and valued. Local communities and groups were advised to increase the availability of

programs and services, improve information about and access to seniors' support services, establish or enhance transportation programs and low-cost leisure and education activities, and involve seniors at all levels of planning. Recommendations for policy makers included increasing barrier-free access, increasing housing options that would foster socialization, improving the availability of seniors' resources in rural and remote areas, providing resources for continuing research on issues of isolation and loneliness. They were also urged to enhance communication and cooperation among all levels of government to foster or improve links among social services, housing, health and education in order to better address issues of isolation and loneliness for older people in a comprehensive manner.

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MENTAL HEALTH ISSUES OF PARTICULAR GROUPS:

**(1) THE DICHOTOMIES OF CAREGIVING:
MENTAL HEALTH CHALLENGES
OF INFORMAL CAREGIVERS**

by

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National Advisory Council on Aging**

Life as a caregiver

When I developed the outline for this article, I thought the hardest part was over. After all, I had been for 14 years a caregiver for my father – a man who suffered from mixed dementia, crippling arthritis, incontinence, aphasia and dysphasia, a man who ended a proud, accomplished long life in a faceless long-term care facility. I had been through it all and believed I understood caregiver emotions and what it is like to have one's mental health and well-being compromised because of love for another.

But as I began to unravel my thoughts and memories, I realized that it is as difficult for me today as it was then to understand what went on in my mind and how these thoughts and emotions changed my life completely.

Logic tells us that caregiving today should be easier than ever. Yes, our health care system is under huge stress; yes, our population is aging rapidly and yes, we live in an age where there is too little time to think about life and our obligations to others and ourselves. But what about the never-ending advances in medical technology, miracle drugs and aids and equipment that allow seniors to live healthier, more independent lives? Don't these realities make up for all caregiving difficulties we face in today's world?

The answer is definitely no. My caregiving experience taught me that because of the long list of physical and cognitive deficits endured by my father, I ended up adding spouse, parent, personal care aide, friend, chauffeur, decision-maker, advocate, personnel manager, financial manager and funeral planner to my role as daughter. How could anyone fill all these roles and emerge unscathed?

There are 4.5 million caregivers in Canada today who are sacrificing all or part of their lives to care for chronically or terminally-ill loved ones. No matter where care is provided – in the home or in an institution – caregivers invariably end up paying for products and services out of their own pockets. In fact, informal caregivers' financial contribution – in the form of subsidizing the cost of services delivered to the home, and in casual expenditures (food, laundry, gas, parking, etc.) – totals about \$100 million a week or more, suggesting that caregivers spend at least \$5 billion a year. Many caregivers report they have had to cut back on their personal

budgets, use up their savings or borrow money to meet their caregiving financial obligations.¹

The economic value provided by family caregivers is enormous. It is estimated that help given to seniors alone saves the public system over \$5 billion per year² and is equivalent to the work of 276,509 full time employees.³

Yet there are no formal, customizable and accessible training programs for caregivers, no 24-hour help lines, no national policies for financial support or job protection and certainly no formal recognition or thanks for putting our lives on hold.

Of course there is help available to caregivers. But what and how much often depends on what province you live in, or whether you live in the city or the country. Getting help also depends on our connection to our community, on knowing the questions we need to ask as well as on our awareness of what we are owed by society and governments. But getting depends mostly on our ability to ask for it.

I have heard professionals say over and over: “Why don’t caregivers ask for help?” “Why do they tell us in surveys what they need and then ignore the services that we develop?” I believe the answer is this: being a caregiver is like walking a tightrope. As long as you hold on to your pole – your support – and maintain your concentration, you may wobble but you will keep your balance and remain upright – physically and emotionally. You don’t feel you need help. But as soon as something begins to shift and your pole becomes unbalanced you start to lose control, you lose your balance and you fall. You still don’t ask for help because you now think it is too late to fix the impossible. There is no escaping this reality where there are problems that can’t be solved, questions that can’t be answered and complexities that can’t be understood — where the only relief comes in someone’s death.

When I read Webster’s definition of dichotomy – a separation into two parts that differ widely from, or contradict each other – I knew I was seeing the essence of caregiving. When you look at most caregivers, you can almost see two people precariously existing within the body of one. You experience a person wrestling

with contradictions that sometimes even she does not see or accept, a person struggling to rationalize extreme polarities.

What are some of these caregiving dichotomies that demand such a delicate balancing act?

Sense of accomplishment vs. hopelessness and despair

Caregiving is a task-oriented and emotional minefield. Most of us can do the physical job. We even take pride in learning how to assist another with dressing, eating or transferring. On a good day we feel useful, even capable, and positive to the point of believing our expert care may in fact influence the course of the illness. We revel in our accomplishments.

But then a fall happens – in the home that we so carefully modified to prevent just such a catastrophe. Our euphoria turns in an instant to despair. We admit the unthinkable: Who am I trying to kid? I can't change things at all; in fact, I barely cope from day to day.

Our fatigue permits us to surrender to the emotional turmoil that is always just beneath the surface. We are torn between knowing we can do the job better than anyone else and admitting that we lack the tools – knowledge about the diseases we face, treatment options, appropriate medications and, more importantly, the experience to make the right decisions when the times inevitably come to make them. We feel helpless; we become hopeless.

Relief vs. guilt

When I made the decision to place my father in a long-term care facility, I was emotionally burned out. I could see no other alternative for either of us. Intellectually, I knew my father needed what I could not give him – 24-hour, two-person skilled care in a safe environment. But I was still overwhelmed with remorse.

I had to admit I felt relieved that someone else would now take over the minute-to-minute care and watch over my father's well-being. The other side of me

raged at my selfishness. How could I do this to my own father, who was so fiercely independent and had instilled this quality in me? How could I put my needs before those of my father, a helpless, frail shell of a human being? The guilt was inescapable and filled me with a profound sorrow that still lives in me today.

Fortunately, time and a wise fellow caregiver taught me a valuable lesson. Placing my father allowed me to concentrate on loving him and not on worrying about him. I was released from the constant tension of doing, so I could now just be with my father, to sit quietly beside him, hold his hand and comfort him with my presence. I had time to quietly care.

The need to control vs. the ability to accept help

Caregivers are renowned for saying: No one knows my loved one better than I do. I can do the job better than anyone else; it is easier if I just do it. Some of us refuse help because we are perfectionists who don't want others to know that we need any help; others come to fear that the caregiving may be taken away from them, robbing them of their reason for living.

I believe what caregivers are really doing is trying to preserve some degree of control over a situation that has spiraled out of control. We need to do it all, yet we also resent being left totally responsible for the life of another. Whatever goes wrong is our fault because we are not working hard enough.

But something else is also going on here. In today's world, we are considered successful if we are capable and independent. As we grow up we learn to regard the need to lean on others as a sign of weakness or as an indication of decline.

Suddenly we become caregivers who are supposed to ask for help, to depend on others. How can we reverse years and years of learned independence virtually overnight without feeling anxiety, confusion and fear – of losing what we have been taught is a requirement for a successful life? Caregivers have lost the war before the first battle is fought. We need to change the rules of the game so that we grow up understanding that we all need others for varying reasons throughout our lives; it is normal and essential.

We must learn to heed the words of one wise old woman who said: “If you accept help you teach the next generation how to give help.”⁴

Anger vs. acceptance

When someone we love falls ill and we know things will only get worse, we get angry. The more we care, the angrier we get because it is all about someone else and not us. Why my father, my mother, wife or husband? We rail against fate, seeing only the injustice of it all, particularly when we must watch a loved one lose his mind to dementia.

Anger is a healthy part of an emotional life. It allows us to admit to and put words to pain so deep it seems unbearable. But when anger consumes, it burns like a raw flame. There is no room for anything positive as everything that we have always cherished starts to die.

Over time, my anger started to give way to acceptance. I learned that I could not change or control what was happening to my father’s mind and body; what I could control was the life I learned to build for my father, one in which he felt safe, loved and protected. There were setbacks but I accepted each new challenge, each change in his capabilities and occasionally felt triumph in my own small way over the seemingly impossible, because I finally accepted the fact that my anger was justified.

Loss vs. gain

How we view our caregiving experience can colour our mental well-being for the rest of our lives. Some look back on their caregiving journey and see only pain and suffering; they see themselves and others as failures because no one was capable of changing the course of events. They continue to experience unending loss – lost companionship, lost time, lost opportunities, loss of self.

In the few quiet times we allow ourselves for contemplation, we have the unhealthy habit of repeating over and over: I should have done more; I should have been there more. Caregivers need help understanding that in giving everything they have to another they end up finding themselves. They need help in rejoicing in their

huge capacity for love and forgiveness – expressed through the selfless act of caring for another. Without this awareness, they may never recover their initial spirit and zest for life. They risk remaining bitter and inconsolable, unable to ever recognize caregiving for what it can be – an incredible opportunity to give the best of yourself to another and realize that you have made a unique difference in someone else's life, a difference no one else could ever have made.

Self sacrifice vs. self preservation

Although many men provide care for others, most caregiving is still performed by women. We learn to associate caregiving with family, duty, and commitment because we learn caregiving from our mothers who held these values that they absorbed from their mothers.

Most women never entertain the idea of saying no to caregiving. Society expects women to sacrifice themselves for others and so we respond to the call. But the call in today's world is not one that lasts for a few weeks or months but one that can last for twenty years. We struggle to be the accomplished wives, mothers and professionals that society expects us to be while seeing our souls and our spirits slowly being extinguished because we cannot be all things to all people, even ourselves. We rage silently at our self sacrifice because we are powerless to stop it.

I was once told that depression equals swallowed rage and I now realize how true those words are. I swallowed my rage so many times caring for my father that I was no longer aware I was doing it. I thought I was functioning, managing my life and my father's; I kept telling myself I was OK. Suddenly one summer morning I could no longer function. In the blink of an eye I felt absolutely incapable. I was diagnosed with depression. I had succumbed to the pressure and the worry and the self neglect even though I believed I could rise above them. I became skilled at meeting my father's needs while becoming totally unable to meet my own. Self sacrifice had won once again.

Grief vs. fulfillment

Grief is a caregiver's constant companion, from the day of diagnosis until after the day of death. It starts with the little things – the inability to go out for

dinner or the loss of a weekend trip. But the grief continues to grow as the losses reveal themselves to the caregiver in crisis after crisis. We know death is coming but we are denied the small joys that can keep us going because we will not allow ourselves to grieve for that moment and then continue on. Small sorrows collect and sneak up on us, preventing us from feeling that we are decent human beings doing the best we can.

When our caregiving days have passed most of us feel too little satisfaction at what we have accomplished. How many of us say to ourselves after the death of a loved one for whom we cared: “I am satisfied with what I did.” As my friend Sandy admitted after her mother’s death: “I think I played the game well but I didn’t win the prize.” I believe very few caregivers allow themselves the peace that comes from knowing that they did everything humanly possible for the sake of another and that it was enough.

Conclusion

Caregiving until the end of life leaves few untouched. In most cases the death of a loved one allows caregivers to heal and move forward, wiser in the knowledge that the circle of life continues as it always has. Dementia, however, imposes its own set of unique sorrows upon caregivers because when the dementia journey is supposed to be over, it’s not over. After this unspeakable injustice has robbed us, the daughters and sons, of those we love, after we manage to shake off the shock, the fatigue and the disbelief over what we have managed to live through, what remains is the dark terror that we will follow in our parents’ genetic footsteps. If a little knowledge is a dangerous thing, what will too much knowledge do to us who are left behind, year after year, after year?

The caregivers of those suffering from dementia spend their days walking a fine line between success and failure, joy and grief – between life and death. There is no tougher task in life. We must encourage caregivers to feel and express the dizzying range of emotions that influence their mental health from day to day. By helping caregivers to openly accept their strengths and weaknesses, their own needs and biases, health care professionals can then normalize these feelings and reactions and allow caregivers to better bear the incredible demands made upon their bodies and souls.

Endnotes

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MENTAL HEALTH ISSUES OF PARTICULAR GROUPS:

(2) GAY AND LESBIAN SENIORS

by

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A lifetime on the margin

We are just beginning, as a society, to recognize the rights of gay and lesbianⁱ people, and to understand the impact that homophobic and heterosexistⁱⁱ discrimination has had upon their lives. Between 1977 and 1998, all provinces, territories and the federal government prohibited discrimination on the basis of sexual orientation, some of their own volition, some due to the 1995 decree of the Supreme Court of Canada. In 1999, the Supreme Court of Canada declared that any provincial law recognizing common law relationships that does not extend equality to same-sex couples is unconstitutional. As a result, provinces have been in the process of introducing bills that change all aspects of policy to incorporate same-sex unions as de facto common-law unions (except in the case of marriage and adoption).

These legal and policy changes might suggest that Canada has become a more open and tolerant nation with respect to gay and lesbian rights. There is some truth to this statement. However, there still exists widespread discrimination against gay and lesbian people across the life span. Gay and lesbian seniors are one group which has been and continues to be particularly vulnerable to discrimination. This is so for several reasons.

First, we must not forget that legal and policy changes are relatively new in Canada. The vast majority of gay and lesbian people who are 65 years old or over, have lived most of their lives in environments of overt discrimination and hostility, at a time when it was commonly believed that homosexuality was a sin, a crime or a mental illness and when there was no protection for gay and lesbian people under the law. In fact, most gay and lesbian seniors today, were already adults prior to the

The term "gay" refers to males who have (almost exclusive or exclusive) feelings of affection and attraction, both emotionally and physically, for other males. Gay is also an inclusive term used by many people to describe anyone who is not heterosexual. The term "lesbian" refers to females who have (almost exclusive or exclusive) feelings of affection and attraction, both emotionally and physically, for other females.

ⁱ The term "homophobia" was coined in 1973 by George Weinberg. For him, homophobia is the irrational fear, hatred and intolerance of homosexuals. For Simkin (1993), heterosexism is the presumption that heterosexuality is the norm and that any other form of sexual expression is deviant.

advent of the gay liberation movement in the 1970sⁱⁱⁱ. This meant that it was almost impossible to be openly gay and be safe from violent attacks, loss of jobs, rejection by family, police arrest, and in many cases, enforced medical treatment.

Second, while the law and government policy are changing, institutions and the professionals that work in them, have been much slower to adapt. This is particularly true of health care institutions which have, up until recently, been one of the largest perpetrators of discrimination and oppression.¹ So that, at a time when senior gay men and lesbians may be facing health concerns as a result of the combined effects of aging and of having had to cope with life-long experiences of discrimination, senior care agencies are not always ready to provide appropriate care.² In fact, in many situations these agencies and the professionals that work in them advertently or inadvertently reproduce oppression. At best, gay and lesbian seniors and their needs are simply ignored.

Finally, there is little knowledge about the experiences and needs of gay and lesbian seniors, making change more difficult to address. This is true both within the mainstream senior care sector and within gay and lesbian community organizations. To date, most of the research on the impact of discrimination on gay and lesbian people has been focused on youth and young adults. There has been almost no recognition of the specific realities of gay and lesbian seniors and their families in practice, policy or research.³ This contributes to their invisibility.

The health and mental health consequences of discrimination and stigma are far-reaching. Gay and lesbian seniors today, who have faced a high degree of marginalization and oppression throughout their lives, have learned to cope and survive in many different ways, but these can exact a high toll over time.^{4, 5} Health and mental health consequences of oppression are only now beginning to be documented and understood. It is for all these reasons that, despite positive change in law and social policy, we must continue to be concerned about gay and lesbian seniors.

ⁱⁱⁱ In the United States, in 1969, due to patrons at a gay bar fighting arrest and oppression, the Stonewall Riots as they came to be known, galvanized the divergent gay and lesbian groups into a movement – the Gay Liberation Movement. Stonewall is observed worldwide as a defining moment in modern gay and lesbian history.

This chapter touches upon some of the issues facing gay and lesbian seniors. We have attempted to highlight the experiences of discrimination and oppression they have faced throughout their lives, particularly within the health care system and the impact this has had on their identity, health and patterns of help-seeking. We also have tried to address the strengths and resilience of gay and lesbian seniors which have been engendered as a result of coping with stigma. Finally, we make recommendations for changes in policy and practice. We have included several quotes from gay and lesbian seniors themselves, their families as well as those from mainstream workers in senior care organizations which were gathered in a national focus group study we completed in 2000, to emphasize issues which emerge from the literature on gay and lesbian aging. We hope that this chapter will contribute much needed information on the experiences of and attitudes towards gay and lesbian seniors in health, thereby reducing discrimination against them.

Who is missing from the current analysis?

It is important to note that the current chapter is limited to discussions about gay men and lesbians. This means that the experiences of bisexual and transgender^{iv} people are not included. While the issues facing these communities are essential to address and have often been identified alongside those of gay men and lesbians, it was felt that the points of view of both bisexual and transgender people are unique enough as to warrant a distinct and separate enquiry. Often times, research which claims to include bisexual and transgender populations alongside gay and lesbian populations, is actually focused almost entirely on the experiences of the latter groups. This reinforces the marginalized and invisible status of bisexual and transgender people.

Given the limited information available on bisexual and transgender aging, we focused our discussion on the experiences of gay men and lesbian only. We recognize and affirm the necessity of expanding funding opportunities so that

^{iv} The term "bisexual" refers to those who have feelings of affection and attraction, both emotionally and physically, for both males and females. The term "transgender" is an umbrella term encompassing the diversity of gender expression, including drag queens and kings, bigenders, crossdressers, transgenderists, and transsexuals. Those who identify as transgender find their gender identity to be in conflict with their anatomical gender.

research can be undertaken on issues of bisexual and transgender aging in the future.

Experiences of discrimination

“... we’re coming out of an experience of being badly treated in society, and there’s no sense that treatment is going to get any better when you get older and more vulnerable within the system.”

“I have been working with caregivers for the past 12 years and never never have we had... have we stopped to think about gays or lesbians. No-one has ever told us that their experience could be different, or that they need something... never!”

Manifestations of discrimination against gay and lesbian people have been and continue to be widespread in Canadian society. Gay men and lesbians have been physically and sexually assaulted and abused because of their sexual orientation by both strangers and people known to them.⁶ They have frequently experienced verbal, emotional and psychological abuse, the more common forms of homophobia.⁶ And they have also faced considerable discrimination in health and social service systems. Because gay men and lesbians have historically been socially defined within medical terms as mentally ill, the health care system has been one of the primary arenas through which control over their lives was exerted. As such, health professionals were often charged with the task of “healing” gay and lesbian people from their so-called unhealthy same-sex attractions through such means as electro-shock therapy or aversion therapy.⁷ In 1973, the American Psychological Association removed homosexuality from the Diagnostic and Statistical Manual, and in 1992, the World Health Organization removed homosexuality from its list of mental disorders. Despite these changes, many health care providers continue to consider homosexuality to be a mental disorder.^{8,9}

Through several studies, we know that gay and lesbian people of all ages have reported a range of various negative reactions from service providers, including: rejection of the patient or exhibition of hostility, harassment, excessive curiosity, pity, condescension, ostracism, refusal of treatment, avoidance of physical contact or breach of confidentiality.

Although these studies document the health care experiences of gay men and lesbians regardless of age, it has been recognized that discrimination in health care is particularly salient for today's gay and lesbian seniors.^{10, 11} Indeed, aging services have often been found to be discriminatory environments in which seniors come into contact with much of the same discrimination faced by all gay men and lesbians in the health care system.¹² In addition, sectors of the aging network in which seniors work (voluntary or social support organizations), or live alongside each other (congregate housing) often expose gay men and lesbians to further marginalization from contemporaries who hold homophobic and heterosexist attitudes.

In recent years, overt discrimination has often been replaced by an atmosphere of silence. This form of neglect must also be seen as an important component of discrimination. Older gays and lesbians are rarely visible in mainstream senior networks, in health care institutions and in society generally. Health care professionals often overlook the importance of addressing sexual orientation. This oversight serves to promote and further marginalize seniors and their care providers. The invisibility of older gays and lesbians in the health care and social service systems also creates important barriers to the development of a social and political voice. Historically, gay and lesbian seniors have been excluded from all discussion, planning, and programming processes in mainstream senior networks. When the needs of gay and lesbian seniors are raised, the most prominent reaction is one of discomfort.¹³

The impact of discrimination on health and mental health

"... but their fear is where they are at, and until they see that the system is inclusive, I think there are some people who are not going to access services when they really could benefit from them until it may be too late."

There is growing documentation which links the experience of discrimination to greater health and mental health problems among gay and lesbian seniors.^{14, 15} This includes the risks of exposure to hostile or intolerant environments, which causes significant stress and often forces people to focus more on assessing the safety of environments rather than on developmental achievements (such as education, employment, family, social networks, etc.).¹⁴ It also contributes to lower life satisfaction and self-esteem. Research has also documented that managing

stigma over long periods of time results in higher risks of depression and suicide, addictions and substance abuse.^{16, 17} As a result of negative reactions, gay men and lesbians have consistently reported avoiding and delaying medical care and examinations.^{18, 19, 20} This can have a negative impact on health care outcomes. For example, research on breast cancer suggests that lesbians have a much higher rate of breast cancer than heterosexual women (one in three compared to one in eight) and that the prognosis among lesbian women is worse because of delayed help-seeking patterns and maltreatment by the system.²¹ Because of the length of time that older gay men and lesbians have been managing stigma, health care professionals should be particularly concerned about providing appropriate and supportive health services to them.

Coming out

“Most people are terrified of going into any of the care facilities, and having to be hidden, losing their lovers, their partners, their friends... so it is a huge question and a tremendous loss of power when you’re not mobile anymore.”

According to the literature, the coming out process plays a crucial role in the health of gay and lesbian people. Researchers have documented that the degree of affirmation of one’s sexual orientation and one’s experience with coming out affect the health of gay men and lesbians.⁸ In spite of its reported importance, however, the disclosure of sexual orientation has been identified as the most problematic component in consulting a health care professional or gaining access to treatment.²² As a result of discrimination, gay and lesbian seniors will often not identify themselves publicly. This has led some practitioners to believe that there are no gay or lesbian seniors or, that all their needs are being met outside of the formal care system. This has contributed to the almost complete invisibility of gay and lesbian seniors in the system and to the lack of attention paid to them and to their issues in institutional and policy bodies in senior care. In this context, it becomes easier for institutions and practitioners to say “sexual orientation doesn’t matter.”¹³

At the level of practice, it is important to understand that, because gay and lesbian people who are 65 or over today grew up prior to the development of a public and vocal gay and lesbian community, many seniors do not identify with gay and lesbian communities, or as gay or lesbian. For example, many people will identify

their same-sex partners as their “friend.” The lack of identity with the gay or lesbian community is often rooted in life-long practices of protection from risk, but can also simply be the result of not having had the opportunity to feel part of a broader cultural group.¹³

Still, many senior gay men and lesbians have chosen to come out. Unfortunately, they are often forced back into the closet when they begin to require supportive aging services. This is so because, confronted with discriminatory environments in the health, social service and housing sectors, older gays and lesbians and their families have to hide their sexual orientation in efforts to reduce the experiences of discrimination.⁷

Caregivers

“One woman told me that she would just like to know that if she ever has to go into a facility, that she can hold hands with her partner in the tv room.”

When we discuss family caregiving in the context of gay and lesbian lives, then we must talk about the concept of “chosen families.” Older gay men and lesbians have sometimes faced rejection by families of origin and, as such, continue to have little contact with them as they grow older. This has required gay men and lesbians to find and create family among their friends.²¹ Research suggests that older gay men and lesbians have more friends than their heterosexual counterparts.²³ Unlike the stereotype of the lonely and isolated senior gay man or lesbian, these people have reported having a diverse array of satisfying social relationships. Older gay men and lesbians often have long-time partners or, in some cases, children who provide the first line of support when a loss of autonomy is experienced. In addition, many older gay men and lesbians have close friends who also provide informal support. For gay and lesbian seniors the “chosen family” is one of the most important sources of support, both in terms of hands-on tasks and accompaniment/advocacy in the health care system.

In the health care field generally, partners and friends of gay and lesbian people requiring health care services have pointed time and again to the lack of rights/recognition given them in relation to visiting, decision-making and caregiving for their loved one.²⁴ This enforced invisibility both results from and has contributed

to the continued lack of exposure to gay and lesbian issues and experiences and the lack of commitment to developing gay-positive policies and practices directed towards elders themselves and their caregivers. It has also resulted in increased stress on both older gay or lesbian people and their families.²⁵

Strength and resilience

“I heard a story once that one lesbian couple... one of the partners changed her last name to her partner’s last name so that they would be taken for sisters. To be put in the same room.”

All of this may seem to paint a very dire picture indeed. However, we must not forget that coping with stigma not only leads to health care problems but can also engender strength. In fact, some research suggests that older gay men and lesbians may be more able to adjust to aging and deal with ageism than their heterosexual counterparts. Developing resilience in the face of discrimination has helped many gay and lesbian seniors become expert in dealing with adversity, facing change and learning how to take care of themselves. This adaptive capacity follows them into old age so that, although unable to rely on public services, senior gays and lesbians have developed a unique capacity to do for themselves and for each other. These adaptive coping strategies, as forms of resilience and resistance, have been well documented in the research.^{3, 21, 26}

What can we do?

“I think that what a lot of people feel is that fear that they can’t be out, that it won’t be safe to be out, that what is required in order to create a kind of safety is some proactive reassurance that this is an open climate.”

It is important to emphasize that homophobic and heterosexist discrimination is not simply a thing of the past; it continues to be present in the senior care network. This contributes to a continued discomfort with and lack of trust in the system. Older gays and lesbians, their families and allies have identified the incredible fear experienced by gay and lesbian seniors when confronted with these services and systems. At worst, the system continues to be hostile. At best, there is a pervasive ignorance about gay and lesbian seniors and their unique needs in the senior care network.

Health care providers and policy makers can play a key role in supporting the health and well-being of gay and lesbian seniors. Education is a crucial tool for change. Educational institutions and professional associations must introduce an agenda supporting gay and lesbian health education. Inclusion of gay and lesbian health curriculum, providing professional training, encouraging presentations and workshops at conferences, supporting and promoting research, encouraging publication and distribution of resource material, developing educational campaigns in the media, and doing outreach are all central policy and practice recommendations. Unique programs designed to redress discrimination and attend to needs must also be developed. Outreach strategies, adapting assessment tools, improving communication and creating open and supportive environments are all necessary tools to better meet the needs of gay and lesbian seniors within the current system.

Gay and lesbian seniors also need to include their partners, significant friends and “chosen families” in their health care interactions and decision-making. These people need to be respected and supported even if and when families of origin contest their involvement. Making this possible in one’s own practice and encouraging the development of institutional policies which ensure that these people are included are central to adapting practice. Finally, connecting individual practice with the larger goals of community advocacy can support positive change and social solidarity for all gay and lesbian seniors and their families.

The role of gay and lesbian communities in bringing about change cannot be understated. Gay and lesbian community activists are in the best position to advocate for changes to the senior care system and to provide education. They have worked for decades on documenting and addressing homophobia and heterosexism in society and can advance an agenda for institutional change. This includes opening up space for gay and lesbian seniors to identify themselves and participate as equals in change efforts. In doing so, gay and lesbian communities will also be better placed to provide community-based senior care programs. Adapting public services while simultaneously creating gay and lesbian-specific community services will best ensure that gay and lesbian seniors have maximum choice in environments of safety and security. Only in this way can we fully promote equity in senior care.

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MENTAL HEALTH ISSUES OF PARTICULAR GROUPS:
(3) SENIORS LIVING IN LONG-TERM CARE FACILITIES

by

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The demographics of long-term care

In recent decades, as the elderly population in modern industrial countries has rapidly increased, the number of seniors receiving care in nursing homes has also risen dramatically. In Canada, the actual number has risen from 203,000 in 1986 to 240,000 in 1996¹ and this number is expected to continue to increase. By 2021, seniors (aged 65 and over) will account for 18% of the Canadian population for a total of 6.7 million people and this increase will likely result in an increased need for long-term care beds. Projections for 2031 suggest that the number of long-term care beds will triple or even quadruple. The population aged 85 and over is growing at the fastest rate and it is this group that are most likely to require long-term care. According to Statistics Canada, in 1996, 38% of all women aged 85 and over lived in an institution, compared with 24% of similarly aged men.² The rate of institutionalization varies somewhat between Canadian provinces. Seniors are least likely to be institutionalized in British Columbia, where 5.4% of seniors live in institutions. In contrast, seniors are most likely to be institutionalized in Quebec, Prince Edward Island or Alberta. (The statistics from Quebec reflect the fact that many seniors in that province are members of and reside in a religious institution.)

Important worldwide trends in nursing home care include: a) a growth in the physical size of facilities; b) an increase in the availability of higher levels of care; c) a significantly greater percentage of residents with dementia and severe cognitive impairment; d) more residents with psychiatric and behavioural disorders; and e) the development of national standards and legislation in some countries.

There is evidence that in Canada, the majority of elderly residents of nursing homes are disabled and require a considerable degree of care and assistance. In 1995, the Canadian National Population Health Survey found that 75% of seniors residing in long-term health care facilities required help with one or more activities of daily living (i.e., personal care, moving about the institution, getting in and out of bed, getting in and out of a chair) and 39% needed help with all of these activities.³ In addition, there is evidence that inability to perform the activities of daily living contribute significantly to the final decision regarding admission to a nursing home.

Mental disorders in long-term care settings

The literature suggests that there is an extremely high prevalence of mental disorder among nursing home residents. Recent studies using sophisticated methods report prevalence rates of between 80% and 90%. The most common mental disorders are listed in Table 1. One of the most rigorous studies was carried out by Rovner et al.⁴ who reported the prevalence of specific psychiatric disorders in 454 consecutive nursing home admissions. More than two thirds of the residents had some form of dementia, 10% suffered from affective disorders and 2.4% were diagnosed as having schizophrenia or another psychiatric illness. Forty percent of the residents suffering from dementia had psychiatric complications such as depression, delusions or delirium. Depression is extremely common in the nursing home setting. Studies suggest that between 15% and 25% of nursing home residents have symptoms of Major Depression and another 25% have depressive symptoms of lesser severity.^{5,6} The incidence of new depression has been estimated to be 12% to 14% per year, with about half of all new cases meeting criteria for Major Depression.

In addition, follow-up studies of patients with mild depression have shown that many are likely to become more significantly depressed over time. It can be difficult to make a diagnosis of depression, particularly in patients with co-existing dementia and/or chronic medical illness. There is evidence to suggest that depression can contribute significantly to a general deterioration of health in seniors. Decreased food and fluid intake may lead to undernutrition, dehydration, weight loss and impaired resistance to infection. Studies also suggest that depression is associated with increased mortality rates in long-term care with a relative risk of between 1.5 and 3, as compared to non-depressed patients.⁷

The prevalence of psychosis in nursing home residents appears to range from 12% to 21% depending on how psychotic symptoms are measured. One study reported that 21% of newly admitted nursing home residents had delusions.⁸ The differential diagnosis of psychosis in the elderly includes many disorders, ranging from schizophrenia to delusional disorder, mood disorders and delirium. Although there are a relatively low number of residents with schizophrenia, this is a particularly difficult group to treat in the long-term care setting. Some seniors who have suffered from schizophrenia for most of their lives have been transferred from

psychiatric institutions to long-term care facilities which generally have limited availability of mental health workers.

Individuals with dementia suffer from cognitive impairment, usually consisting of memory impairment and difficulty in at least one other cognitive area. In addition to memory disturbance, many residents with dementia also have behavioural problems which include agitation, aggression, wandering, repetitive or bizarre behaviours, shouting, disinhibited behaviours and sexually inappropriate behaviour. Agitation has been defined as “inappropriate verbal, vocal or motor activity unexplained by apparent needs or confusion.” Agitated behaviours can be categorized as disruptive but non-aggressive, socially inappropriate or aggressive. Aggression can be defined as hostile actions directed towards others, the self or objects and can be categorized further as physical, verbal or sexual. A review of the literature regarding the prevalence of the behavioural and psychological symptoms of dementia reported median figures of 44% for global agitation, 24% for verbal aggression and 14% for physical aggression.⁹ Individuals who demonstrate signs of acute confusion may be suffering from delirium, which is a generally reversible condition precipitated by a physical illness or drugs. Patients suffering from delirium may be extremely agitated or alternatively may become withdrawn and drowsy to the point of stupor.

Creating an environment to optimize mental health

The creation of a positive, supportive environment and the provision of good care can contribute to the mental health of residents in long-term care. Borson and colleagues¹⁰ note that long-term care “emphasizes maintenance of functional capacity, delaying the progress of disease when possible, and the creation of a safe, supportive environment that promotes maximal autonomy and life satisfaction. The overarching philosophy of good long-term care is the preservation of dignity and purpose in the face of dependency and decline.” Edelson and Lyons¹¹ have emphasized the need to individualize care and promote a sense of mastery in the residents in order that they can feel a sense of trust in and some control over their environment. In addition, they stress the importance of understanding the meaning in the impaired resident’s behaviour. They have also pointed out that an understanding of “the system” is critical and that an institution is like a living organism. It is important to battle against nihilism, cynicism and resistance to

change which may be present in geriatric institutions.

In the United Kingdom, the Centre for Policy on Ageing¹² published a report called “A Better Home Life: The Code of Good Practice for Residential and Nursing Home Care.” The report outlines principles underlying daily life in the continuing care setting which are listed in Table 2. Respect for privacy and dignity is noted to be paramount, with emphasis on the need for residents to have their own individual private space as well as opportunities to choose how they dress, what they eat, when they go to bed and get up and how they should spend their day. In spite of dependence on staff for help with personal care, it is essential that dignity be maintained and privacy respected. Residents should always be treated as adults and staff should avoid adopting patronizing attitudes or behaviours towards residents. It is essential to maintain self-esteem of residents which can be enhanced if they feel valued. The potential contribution of residents to the life of the home should be emphasized. Some homes have created built-in showcases outside of each resident’s room which can contain photographs and memorabilia which highlight the individual achievements and background of the person. Independence should be fostered and residents should be assumed to be competent until proven otherwise. Wherever possible, residents should be able to make decisions for themselves, retaining as much choice and control as possible.

There should be recognition of diversity and individuality, including ethnic, cultural, social and religious diversity. Residents should feel that their needs “will be responded to willingly by staff who understand the value of maintaining a sense of continuity and identity based on past traditions and practices.” Opportunities should be made available for the expression of religious and political beliefs. It is important to create a safe environment and to help the residents to feel safe. Nevertheless, responsible risk taking should also be considered normal and an important component of maintaining autonomy and independence. For example, residents should not be discouraged from undertaking certain activities solely on the grounds that there is an element of risk. It is necessary to find optimal balance between risk and safety. Citizens’ rights should be protected with particular emphasis on protection against and prevention of abuse, theft, exploitation and fraud. It is essential to nurture sustaining relationships with relatives and friends and their participation should be encouraged whenever residents desire it. Finally, the provision of leisure activities, both within and outside of the home, is critically

important. Staff should be sensitive to individual tastes and capacities and try to be flexible enough to match the needs of the residents with the resources of the home. Where possible, the resources of the community should be mobilized to support the activities of the home.

Many of these principles can also be found in the recent Canadian book entitled “Continuing the Care: The Issues and Challenges for Long-Term Care.”¹³ In this book, Young¹⁴ describes the quality factor in long-term care. She describes the process by which standards of care and practice are defined and monitored across Canada and describes the role of many organizations, including the Canadian Council on Health Services Accreditation (CCHSA). She notes that an increasing number of long-term care organizations have embraced newer concepts of care which promote individuality and choice for clients. Some organizations have adopted the “Eden alternative,” the goal of which is to improve the quality of life for residents in nursing homes, in particular to eliminate loneliness, helplessness and boredom. The emphasis is to promote a home-like environment and, in particular, to introduce animals, birds, plants and children into the environment. Malot and Milke¹³ provide an excellent overview of environmental design in long-term care in the same book. The impact of a consumer-oriented model of care on design is outlined.

Caring for residents with mental health problems

The most critical component of mental health care in these settings is provided by the front-line staff. Much of the care is provided by health care aides with nurses, primary care physicians and social workers also playing a vital role. The need for support and education of the staff is frequently highlighted, although resources for its provision are limited. Conn et al.¹⁵ have written a handbook, which is designed to provide a toolkit to enhance the ability of the staff to provide mental health care. The availability of expertise from mental health professionals in Canadian long-term care facilities is quite variable. Little data are available, although a study carried out in Ontario¹⁶ revealed that 88% of responding homes received five hours or less of psychiatric care for their whole facility per month. A recent survey of all members of the Canadian Academy of Geriatric Psychiatry found that 79% of responders provided consultations to a long-term care facility.¹⁷ On average these psychiatrists spend 19.5% of their working week in these facilities

and consult to an average of 5.8 different homes. A survey of psychiatric consultation to nursing homes in six American states revealed that 47% of responders felt that the frequency of on-site consultation was inadequate.¹⁸ When asked to rate adequacy of function, the majority believed that diagnostic assessment and medication recommendations were adequate. However, advice on non-pharmacological management techniques, staff support and dealing with staff stress and family conflicts was largely viewed as inadequate. The authors note that the perceived need for psychiatric services is far greater than the level actually provided. They suggest that more attention must be directed to identifying incentives for psychiatrists to practice in nursing homes, determining clinical effectiveness of mental health services and examining the effects of alternative payment mechanisms on level of care.

The first stage of any mental health intervention should be a comprehensive assessment. Following this it is necessary to make a diagnosis and develop a formulation using a biopsychosocial model, which will guide the clinician with respect to appropriate interventions. These interventions may include behavioural, psychosocial or pharmacological therapies. An increasing number of studies of pharmacological interventions have been carried out in nursing homes. Several studies suggested that antidepressants are effective.

Three recent large-scale studies show that the atypical antipsychotic medications, olanzapine and risperidone, are effective in treating psychosis and aggression associated with dementia.^{19, 20, 21} For the care of individuals with challenging behaviours, behaviour management strategies can be very effective. It is important to pay attention to a) cognitive deficits and the manner in which these compromise everyday functioning; b) environmental factors that trigger and maintain challenging behaviours; and c) staff attitudes, perceptions and expectations. Landreville and colleagues²² carried out a critical review focusing specifically on behavioural interventions. They concluded that empirical evidence suggests that behavioural approaches are effective. Opie et al.²³ and Cohen-Mansfield²⁴ have recently carried out detailed reviews with regard to the efficacy of non-pharmacological interventions for behaviour disorders associated with dementia. The authors suggested that despite scientific weaknesses there was some evidence to support the efficacy of activity programs, music, behaviour therapy, light therapy, caregiver education and changes to the physical environment. Cohen-Mansfield

reviewed 83 studies and reported that few studies used a control group or a controlled condition. Nevertheless, in every category of intervention, the majority of studies found a lessening of inappropriate behaviours and 53% of the studies found a significant improvement during treatment as compared to baseline. Although psychotherapies (“talk therapies”), including individual and group therapies, can be helpful for some nursing home residents, the availability of appropriately trained staff to deliver these services is quite limited.

Because of concerns regarding poor care, misuse of physical restraints and psychotropic medications, as well as inappropriate placement of some residents, federal legislation in the United States, termed the Omnibus Budget Reconciliation Act of 1987 (OBRA ‘87), was enacted. The regulations require pre-admission screening and an annual resident review as well as requirements for comprehensive assessments using the Minimum Data Set (MDS) or equivalent instrument. The regulations also restrict the use of physical restraints and provide strict guidelines for the use of psychotropic medications, particularly antipsychotics.

Improving care in Canadian long-term care facilities

A Canadian invitational symposium on Gaps in Mental Health Services for Seniors in Long-Term Care Facilities was held in Toronto in April 2002. The goal of the symposium was to engage all relevant stakeholders in discussion and to identify and implement action plans to improve mental health for seniors living in these facilities. Representatives of 65 national and provincial organizations met for two days and at the conclusion of the symposium, the group strongly endorsed a plan to create the Canadian Coalition for Senior’s Mental Health. During the first phase, the work of the Coalition will focus on long-term care. A series of working groups are being formed which will focus on education, research, the environment, human resources, assessment and treatment, and advocacy/public policy. It is hoped that through collaboration, organizations and individuals can work together to promote and improve the mental health of Canadian seniors.

Table 1

COMMON MENTAL DISORDERS IN RESIDENTS OF LONG-TERM CARE FACILITIES	
<ul style="list-style-type: none">• Dementia• Delirium• Mood disorder due to a general medical condition• Psychotic disorder due to a general medical condition• Personality change due to a general medical condition• Major depression• Dysthymic disorder• Adjustment disorder• Personality disorder	

Table 2

THE PRINCIPLES UNDERLYING DAILY LIFE IN A LONG-TERM CARE SETTING	
<ul style="list-style-type: none">• Respect for privacy and dignity• Maintenance of self-esteem• Fostering of independence• Choice and control• Recognition of diversity and individuality• Expression of beliefs• Safety• Responsible risk-taking• Citizens' rights• Sustaining relationships with relatives and friends• Opportunities for leisure activities	

(Source: The Centre for Policy on Ageing, UK, 1996.)

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**BEST PRACTICES FOR THE
MENTAL HEALTH CARE OF OLDER ADULTS**

by

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Background

The development of best practices for the mental health care of older adults, specifically, came about in reaction to the *Best Practices for BC's Mental Health Reform* that were published in British Columbia, in 2000. It was recognized by many of those working with seniors with mental health problems, that this “Best Practices” document neither recognized nor adequately addressed the unique needs of older adults.

Older adults experience many of the same health problems as younger adults, but they are also more likely to experience particular mental and physical health problems unique to the process of aging. Further, older adults are more likely to experience multiple health, social, financial and other problems that lead to complexity in all aspects of planning and providing care services.¹ It was believed that the development of guidelines for best practices in mental health care for seniors would help to identify care needs, particularly those that are not met in existing service systems, and to provide models and examples to assist health managers implement changes that will work to meet those needs.

The *Guidelines for Elderly Mental Health Care Planning for Best Practices for Health Authorities* developed in British Columbia are an example of a collaborative process in developing a planning and practice tool in the field of mental health. The British Columbia Psychogeriatric Association (BCPGA, a multidisciplinary association of clinicians, researchers, educators and others interested in seniors' mental health), along with others, advocated for the development of best practices in mental health appropriate to older adults. As a result, the BCPGA and MHECU (Mental Health Evaluation Clinical Unit, University of British Columbia) were invited by the provincial Ministry of Health and Ministry Responsible for Seniors, to co-chair a steering committee to undertake this task.

The *Guidelines for Elderly Mental Health Care Planning for Best Practices for Health Authorities* reflect a consensus in the field of seniors' mental health, about what constitutes best practice. A working group wrote the first draft of the Guidelines, based on literature reviews and initial discussions with practitioners in the

seniors' mental health field. Consultation on the draft was then sought through focus group discussions with seniors and family members, and from representatives of interest groups and practitioners in the field, in order to elicit information and advice based on expertise and first-hand experience. The draft document was repeatedly circulated for feedback, and the criticisms and suggestions made were incorporated into the final version. The Guidelines thus represent a realistic and accurate representation of actual systems, practices and underlying principles.

The resultant document thus serves two purposes: 1) it provides a model for the development of best practices guidelines, and 2) it provides a real set of best practice guidelines that can be used for future research, policy and practice in the field of seniors' mental health care services.

Issues, gaps and successful strategies in mental health care for seniors discovered through the consultation process

During the process of discussions, consultations and circulation of the draft document, *Guidelines for Elderly Mental Health Care Planning for Best Practices for Health Authorities*, many client/patient needs not being met by the existing service system were identified. Clinicians and managers expressed frustration about recognizing the existence of these needs, but being unable to find or adapt existing services to provide the services or supports that were needed.

General obstacles to establishing or changing existing services that were cited included limited funding, inequities in focus between acute care services and community-based services, lack of or limited expertise locally in assessing and treating the problems of older persons and an underlying ageist perspective that lies latent in the general public consciousness as well as among health care decision-makers whose focus does not extend far beyond services for younger populations.

A variety of local difficulties in particular communities were also identified by those providing feedback, including lack of hospital assessment and treatment beds for the older persons with mental health problems, lack of trained service providers and lack of community support services for family caregivers. Even the lack of simple amenities and diversions that provide quality to daily life was cited,

as in this communication from one family member: "... this principle [of comprehensive services] needs to elaborate that the mentally ill senior is capable of enjoyment with some quality of life experience. This experience may be sporadic but is important and will not happen unless the staff believe it is important and provide opportunities.”² Attitudes and beliefs about seniors are thus as important a consideration as the bricks and mortar of housing options and the organizational patterns of care services.

A further need underlying the development of the *Guidelines* was the recognition that quality mental health care services are not evenly distributed and available across the province. While most communities and regions in the province express the need for more and better services, glaring disparities exist in basic resources between larger, urban areas and small rural communities. The *Guidelines* thus serve to identify the elements of a “gold standard” in psychogeriatric care as well as specific projects and services that work well in a variety of geographical and demographic locales. A one-size-fits-all practice model clearly is not appropriate when communities differ with respect to local capacities, needs and resources.

Stresses and pressures on existing services that affect the senior population in specific ways were also revealed during the consultations. Community services and supports such as intermediate care beds, home support, and other community services, are increasingly needed by increasing numbers of older adults. When demand for community services exceeds supply and when frail, older patients are admitted to hospital with disturbances in cognition or behaviour, they often remain in hospital longer than is necessary. At a time when some provincial governments are actively seeking ways of reducing health care costs and are considering reductions in the number of beds in acute care facilities, these “bed blockers,” as they are often called, are perceived as putting additional pressure on inpatient beds and emergency rooms. A balanced development of community and hospital services would be well served by the *Guidelines*.

As significant as the obstacles named were, many innovative and successful service arrangements and care provisions came to light as reviewers of the draft document offered examples from their local communities. These examples are provided in an appendix to the document and range from relatively simple efforts

such as setting up a communication network for facility nurses to help enhance their knowledge about the mental health needs of older clients to more complex projects in establishing comprehensive community services.

Underlying assumptions of the *Guidelines*

The core principles and recommendations of the *Guidelines* rest on some key assumptions. The first assumption is that the *Guidelines* are intended to apply to services for a particular, target population of seniors experiencing mental health problems:

Elderly people with mental health problems is a general term used to describe people over the age of 65 who have emotional, behavioural or cognitive problems that interfere with their ability to function independently, which seriously affect their feelings of well-being, or which adversely affect their relationships with others. These problems have a variety of biopsychosocial determinants and methods of treatment and care. People under the age of 65 who have conditions more commonly seen in elderly people, such as early dementia, are included in this group.³

Following from this definition of the target population, the goal of seniors' mental health care is defined as:

*...the reduction of distress to the client and family, the improvement and maintenance of function, and the mobilization of the individual's capacity for autonomous living. These should be the goals for all clients, whether living at home or in institutions: a degree of autonomy should be possible in all settings. Independence should be maximized and maintained at the highest level that can be reached.*⁴

It is further assumed that services should be appropriate to the level of need. The majority of individuals with mental health difficulties, primarily dementia and depression, are cared for by family and/or home support, home nursing and family physicians. If a decline in their ability to live in their own homes occurs, seniors may move to assisted living or residential care services. A small number of these

seniors require more specialized services. A comprehensive system of services should provide a continuum of supports and services that begins at the primary level of care (self and family care, family physicians, community supports, such as home support/nursing and day programs) and moves to secondary (residential, specialized outpatient/outreach teams) or tertiary levels (tertiary inpatient) as the complexities of care increase. Emergency services, provincial outreach programs, telemedicine psychiatry and research are also important and are understood to be necessary components of a comprehensive service system as well.

Finally, it is assumed that while services should reflect demonstrable evidence of quality, there is no one “best” service that is appropriate for all situations or communities. Local resources, local demographics and other local factors will differ between communities, and what works “best” in one community can be different from the way in which another community develops a quality service. Realistic goals and objectives and regular evaluations to determine if services meet the test of achievable, appropriate, high quality services are basic requisites of a best practices approach.

Components of the formal service system for seniors’ mental health care

The major components of the health care system are traditionally defined as primary, secondary and tertiary. The *Guidelines* describe each of these components:

The primary level of care is the backbone of the seniors’ mental health system and is frequently the point of entry into the formal service systems. At this level, preventive, diagnostic and therapeutic services are provided by general practitioner or family physicians, home care nurses, home support workers and other community health care providers.

More specialized preventive, diagnostic and therapeutic care is available in the secondary level of care. Community-based outreach teams, day hospital programs, acute inpatient and outpatient care are examples. Only a small percentage of older adults (about 3% of the seniors’ population) have problems that require services at this level of specialized expertise.

The most highly specialized professional services are provided at the tertiary level of care and are needed by an even smaller number of older persons (about 0.5% of those with mental health problems). University research clinics and psychiatric hospitals are considered to be tertiary services.

Key elements and approaches to care

The *Guidelines* identify the basic system elements and approaches to care for older persons that are embodied in best practices. These key elements and approaches to care are necessary system requirements, regardless of community size or location, service sector or type of health care provided, and are summarized below:

Education: Knowledge is the cornerstone of any service system. Clients, family and informal caregivers need a basic understanding about what is happening with older persons experiencing a mental health problem as much as the formal care providers need specialized expertise in the complexities of mental and physical health care.

Family support and involvement: Because the majority of care is provided by family caregivers, it is vital that support be provided to maintain their physical and mental health needs. Further, family members have a wealth of knowledge that formal caregivers do not have, and their involvement in decisions about care will add immensely to the outcomes.

Psychosocial rehabilitation and recovery: Helping older adults find pleasure and meaning in their lives and providing supports that help them retain as much control over their lives as possible are as important as medical or other interventions. The aim of psychosocial rehabilitation is to promote optimal performance in cognition, interpersonal skills, self care, leisure and accessing of community resources.

Environmental milieu (housing): Housing is recognized generally as a critical determinant of health. As important as the physical structure is the social environment. An optimal environment creates a milieu in which individuals do more than just exist; they experience quality of life, finding pleasure in their retained

strengths and assistance with tasks they can no longer perform independently.

Integration and continuity of services: Case management and integration of information systems are the basis of client-centred care. Many different options for integrating services and providing continuity are possible. Each community or region can design models that reflect and meet local resources and needs.

Quality improvement and evaluation: Defined quality improvement processes are important for developing ongoing efforts to improve performance of the care system. Regular reports using a defined template should be produced in order to monitor and evaluate whether or not goals and objectives are being met and to identify changes that are required to meet changing patterns and trends and to improve care outcomes.

Volunteers, mentors and peer counsellors: The “work without remuneration”⁵ provided by the many individual and organizational volunteers is an important component of the informal system of care for older persons with mental health problems. These individuals who volunteer their energy and time also need to have adequate knowledge about the problems and needs of the people they are helping.

Advocacy and protection: Vulnerable individuals must be protected and assisted in accessing services that they need and to which they are entitled. Legislation that enables and supports advocacy and protection is one important component of the care system; funding for agencies and organizations that provide advocacy and protection services is equally important to ensure that the legislation and the available services are used properly.

Health promotion and prevention: Promotion of wellness and prevention of illness or injury must be given high priority to ensure that individuals do not suffer needlessly.

Principles and recommendations

The *Guidelines* identify six principles, based on the BCPGA principles of psychogeriatric care, with auxiliary corollaries that are necessary requirements for

the development of best practices in the care of older persons with mental health problems. Each principle is accompanied by one or more recommendations to health authorities and health care decision makers for developing and implementing high quality services seniors.

Principle 1: Client and family centred (client and family directed where possible but always client centred)

- Maintains the dignity of older adults and treats them with respect
- Involves the person and the family in care planning and management
- Is culturally sensitive
- Is sensitive to the complex and unique ethical issues that arise in the context of decision making about care for older persons, especially those with significant mental health concerns and end of life decisions

Recommendations:

- 1.1 Ensure the physical and social environment in which care is provided is developed as a therapeutic tool, including a shift in focus from tasks to relationships.
- 1.2 Develop and foster a culture of caring across the spectrum of care that acknowledges the need for a meaningful life (rather than just living) and recognizes people's relational needs. A culture of caring would prevent alienation, anomie and despair that many older persons feel and would promote optimal mental health.

Principle 2: Goal oriented

- Reduction of distress to the person and the family
- Improvement and/or maintenance of function
- Mobilization of the individual's capacity for autonomous living
- Maximization and maintenance of independence at the highest level possible

Recommendations:

- 2.1 Establish a culture of caring that includes principles of psychosocial rehabilitation to maximize quality of life for this population. These principles emphasize the importance of consumer involvement in developing and realizing their own personal care and life goals. The need for treatment and supports that help consumers manage their symptoms and build on their strengths is also recognized.
- 2.2 Provide increasingly supportive or assistive environments, driven by clients' changing needs, when maintenance of function is not possible (e.g., in deteriorating cases of dementia).

Principle 3: Accessible and flexible

- User-friendly
- Readily available
- Responsible service that listens to and understands the problems and acts promptly and appropriately
- Takes into account geographical, cultural, financial, political and linguistic obstacles to obtaining care
- Integrates services to ensure continuity of care and coordinates all levels of service providers, including local, provincial and national governments with community organizations
- Individualized to provide services to each person wherever most appropriate (e.g., residence, hospital)

Recommendations:

- 3.1 Formalize defined links for transitions between acute care, facility care and community-based services. These relationships should be defined locally according to the needs of the population, existing resources, the size and location of the community and the local environment. The need for a formalized, collaborative approach is also required in the area adult mental health.

- 3.2 Ensure all staff caring for this population have appropriate skills. This includes acute care and crisis response/emergency services staff.
- 3.3 Develop and adopt, in partnership with the provincial government, competencies expected of professionals working with this population.
- 3.4 Provide access for clients, families and other informal caregivers to education, emotional support and support services, including crisis services.

Principle 4: Comprehensive

- Takes into account all aspects of the person's physical, psychological, social, financial and spiritual needs
- Makes use of a variety of professionals, resources and support personnel to provide a comprehensive range of services in all settings, including the community, facilities and acute care

Recommendations:

- 4.1 Implement a biopsychosocial model of care that addresses the biological, psychological and environmental needs of the population being served. A biopsychosocial model moves the locus from individual pathology alone to a consideration of the whole person within the context of their social environment.
- 4.2 Ensure all teams, regardless of size, include service delivery (direct and indirect), education and quality improvement as part of their mandate. In order to perform these roles, team members require access to ongoing education and consultations with other professionals in the field.
- 4.3 Develop a team approach, regardless of the size of the community, which utilizes a variety of skills in a collaborative manner, ensuring attention to team dynamics and functioning.
- 4.4 Ensure family members are included as part of the care team.

- 4.5 Ensure nonmedical community service providers, such as police, service clubs and volunteers who assist seniors in various ways, are also part of the larger care team.
- 4.6 Develop and establish clear lines of authority to handle crisis response/emergency services. It is appropriate for all clients in crisis to remain connected with their family physician. The family physician can liaise with the secondary or tertiary services as required to handle the emergency. Excellent communication between the client's family physician and secondary and tertiary referral personnel is a must in all circumstances.
- 4.7 Develop the ability to provide intensive at-home care as needed in crisis and urgent, time-limited situations. This could include respite, home support and added care.
- 4.8 Develop preventive interventions, including strategies for maintaining wellness, and early interventions for mental health disorders. Incorporate this information into specific training programs for both informal and formal caregivers.
- 4.9 Expand, in partnership with government and academic research organizations, psychogeriatric outreach to rural and remote communities. This expansion should include more consultations by a broad range of disciplines using modern technology as appropriate (e.g., telehealth).

Principle 5: Specific services

- Recognize the needs of older adults with mental health problems are qualitatively different from mentally well older adults
- Recognize the needs of older adults with a mental health problem are qualitatively different from the younger population with a mental health problem
- Design appropriate and relevant services specifically for this population

Recommendations:

- 5.1 Ensure access to secondary and tertiary services.
- 5.2 Provide support to the primary and secondary service system through increased, ongoing education.
- 5.3 Maintain and continue to develop the specialized body of knowledge and expertise within geriatric mental health.
- 5.4 Identify the unique service needs of older people with mental health problems (outpatient and inpatient) and develop plans for meeting those needs with adequate and appropriate resources.
- 5.5 Ensure staff that work with older people, regardless of their discipline or job, are supported to maintain knowledge and skills needed to provide informed and competent service.

Principle 6: Accountable programs and services

- Accept responsibility for assuring the quality of the service delivered and monitors this in partnership with the client and family
- Respond to reasonable expectations from clients, families and those providing service
- Anticipate and responds to changing demographics
- Incorporate relevant evaluation strategies and research findings to determine optimal methods of service delivery

Recommendations:

- 6.1 Health authorities, in partnership with government, complete a formal evaluation of medium and long stay tertiary psychiatry beds for the elderly to assist in further planning and/or development of these resources.
- 6.2 Develop and adopt, in partnership with government, a standard framework for

describing services to help compare types and amounts of services across the province. This would include:

- Standardized elements that constitute “a case”;
- Ways to track indirect work, including telephone consults, discussions about cases with other professionals and educational sessions; and
- The development of standardized quality improvement criteria, including access criteria, discharge criteria, case loads, staffing benchmarks and outcomes.

- 6.3 Employ a variety of methodologies and approaches to monitor and evaluate the clinical effectiveness of all programs and innovations in the provision of care.
- 6.4 Once every two years, compile a report of services for elderly people with mental health problems in the health authority and submit it to the appropriate government ministry for the development of a provincial report.
- 6.5 Support local accreditation and program evaluation of elderly mental health care services.
- 6.6 Encourage and support research on mental health and aging, service delivery models and programs.

Conclusion

The *Guidelines for Elderly Mental Health Care Planning for Best Practices for Health Authorities* developed in British Columbia meet the essential conceptual requirements of a best practices model:

- The basic elements required in a system of care for older persons with mental health problems are identified and delineated.
- Directions for planning and taking action are provided in the Principles and recommendations.

- The elements, components and directions for planning and action reflect real world appropriateness and achievability as well as meet the requirements of high level policy.
- The *Guidelines* were developed through a collaborative process involving practitioners in the formal system of care, family members and organizational representatives, policy and health care decision makers and incorporating both experiential and research evidence.
- The best practices approach reflects a dynamic process in which the potential for innovation is emphasized to enable changes and adaptations that correspond to local variations in communities, needs and resources.

Development of *Guidelines* may encourage and support long term planning to ensure that the various obstacles to providing optimal mental health care to older adults are overcome, and that services are appropriate and accessible in the future.

Although the *Guidelines* were developed in British Columbia, we believe that they are equally applicable to other parts of Canada, and they have been, in fact, shared with Alberta and Manitoba.

We are hopeful that with the *Guidelines* as a prototype that can be adapted to local conditions, addressing the mental health needs of older adults from a best practice perspective will be an achievable priority for all provinces.

Endnotes

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**THE CARE AND TREATMENT OF PEOPLE
WITH DEMENTIA AND COGNITIVE
IMPAIRMENT: AN UPDATE**

by

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What is dementia and what causes it?

Dementia is a brain disorder that affects thought and behaviour. Several areas of thinking are affected including memory, language, reasoning, and judgement, resulting in significant interference with daily activities. In addition to changes in thinking, some people with dementia may also show behaviours such as wandering, aggression and noisiness. The number and frequency of these challenging behaviours often increase as cognition declines¹ and they are a major factor contributing to institutionalization.² Studies examining the prevalence of behavioural symptoms have reported rates ranging from 20% to 90%.^{3,4} Many factors could account for the wide range in the reported prevalence for these behaviours; they include the level of cognitive impairment, functional abilities, the environmental and social contexts, and the level of caregiver expertise in preventing and managing behavioural symptoms.

Dementia affects both sexes and all socioeconomic and ethnic groups. In Canada, dementia affects 2.5% of those aged 65 to 74, increasing to 34.5% of those 85 years and over. Because our population is rapidly aging, these figures translate into a major health concern for the years to come. It is expected that by 2021, the number of Canadians with dementia will increase by 63% to approximately 592,000.⁵

Alzheimer's disease (AD) is the most common form of dementia and is characterized initially by memory impairment followed by progressive cognitive decline. In the early stages of this disease, most people are still able to make health care decisions and complete financial transactions. In the later stages, however, individuals are often totally reliant on others for care. Other kinds of dementia include dementia due to large or small strokes (vascular dementia), dementia due to Lewy bodies (round deposits in the brain which contain damaged nerve cells), including Parkinson's disease, and a group of dementias characterized by early signs of socially inappropriate behaviours but with relatively preserved memory (frontotemporal dementias). These dementias occur less frequently than AD and may occur in combination with AD.

Mild cognitive impairment

It is important to distinguish between memory changes that are associated with the normal aging process and those that are indicative of a dementia. Some older people may experience more memory loss than is expected for their age but not all will develop dementia or show further degeneration of their abilities. The prospect that early pharmacological intervention may delay progression to dementia has heightened the interest in accurate identification of those who are at risk of developing dementia. The Alzheimer Predictive Index was derived to improve identification of those at greatest risk of developing AD.⁶ If this index is correctly applied to people who have memory impairment and are not demented, its accuracy is 89% in predicting an individual's onset of AD in two years. Further research in this area is essential to determine whether the course of the disease can be altered by early application of treatments.

Treatments for dementia and cognitive impairment

In this section, we will describe the psychosocial, environmental and pharmaceutical interventions that have been found to be effective in enhancing cognition and promoting positive behaviour in people with dementia and cognitive impairment.

Psychosocial interventions

Psychosocial interventions discussed in this review include treatment strategies directly applied to the person with dementia or to caregivers, including behaviour modification, activity programs, cognitive training and psychoeducational training programs. The goals of psychosocial approaches are to enhance functional performance, such as self care abilities, to reduce problem behaviours, such as wandering or aggression, to improve cognitive functioning and to improve caregiving strategies.

Direct interventions primarily for functional behaviours

The American Academy of Neurology⁷ recommended that behaviour modification, scheduled toileting and prompted voiding routines be considered a standard for practice in the management of **urinary incontinence** in people with dementia. However, it has been found⁸ that these approaches, while effective with some patients, showed the least benefit in nursing home residents who were the most severely impaired, least mobile and had the greatest frequency of incontinence. Given the labour cost of toileting programs, the authors concluded that prompted voiding routines will be most effective if focused on those most likely to benefit, otherwise palliative measures may be appropriate.

Graded assistance, which includes verbal prompts and physical demonstrations to complete physical assistance, supplemented by practice of skills and positive reinforcement, has been used in patients with dementia. This approach has been found to improve **basic activities of daily living** (e.g., dressing, eating, ambulating, toileting, hygiene) and **instrumental activities of daily living** (e.g., shopping, housework, accounting, food preparation, transportation).^{9, 10, 11, 12} Based on the quality of the evidence, the American Academy of Neurology⁷ considered graded assistance, practice, and positive reinforcement to be a guideline (not a standard) for practice to increase functional independence. However, the Academy concluded that there was lack of conclusive supporting data for the beneficial effects of low lighting levels, music, simulated nature sounds, or intensive training that incorporates multiple group therapy approaches on activities of daily living.

Validation therapy, a method of communicating with very old people in a way that provides empathy and acceptance⁸ was reviewed in the Cochrane Library. Only two studies could be found that evaluated validation therapy for communicating with old-old people with dementia. The review of these studies showed that the therapy does not provide conclusive results although there does appear to be some positive effects such as more **self care**, more **social behaviour**, better **morale**, and less **disorientation**. The authors concluded that there was a need for more research specifically to examine the effectiveness of validation therapy as a function of the severity of cognitive impairment.

Direct interventions primarily for disruptive behaviours

A study was conducted to compare a behavioural management technique with trazedone, haloperidol (anti-psychotic drugs) and placebo for **agitation** in people with AD who resided in the community with a regular caregiver.¹³ The behavioural approach consisted of 16 weeks of treatment sessions that provided information about AD, strategies for decreasing agitated behaviours and structured training programs. No differences were found between any active treatments and placebo. The authors concluded that more effective pharmacologic, nonpharmacologic and combination treatments were needed. However, the patients in this study were less severely impaired and not as behaviourally disturbed as in other studies thus reducing the amount of improvement that could be expected. Further research is clearly needed.

Interventions including music, the use of family-generated videotapes, and one-to-one social interactions⁴ were all found to be more effective than no treatment in the immediate short-term reduction of **verbally disruptive behaviours**. Music intervention was the least effective of the three interventions. In another study¹⁴ based on nursing staff observation logs but not based on direct observation, audiotaped telephone conversations from a loved one were found to reduce **withdrawal** and **agitation** more than usual care. In a series of seven case studies in long-term care residents who had severe dementia, **verbally disruptive behaviours** were reduced in only three patients by conditional social interaction, massage, and provision of distracting stimuli such as music, conversation or touch.¹⁵ The investigators did not compare the individual effectiveness of the different interventions but concluded that it was the extra one-to-one interaction given during the intervention that was effective in reassuring and calming those residents who showed benefits.

Individual and group activity programs offered in residential facilities were systematically reviewed. **Aggressive behaviours** were reduced in a daily 90-minute walking program and episodes of agitation fell significantly with a program that offered daily 40-minute gentle exercises.¹⁶ Several studies have shown that music selected on the basis of patients' preferences reduced problem behaviours such as **agitation, aggression, and mood disturbances**. Additional

studies using small samples have reported that bright lights reduced **aggression** and **agitation**, written prompts for repetitive questions reduced those vocalizations, and walking and light exercises reduced **wandering, aggression, and agitation**.⁷

In their practice recommendations, the American Academy of Neurology⁷ recommended that music, particularly during meals and bathtimes and walking or light exercises be considered practice guidelines for the management of behaviour problems in persons with dementia. On the other hand, they considered that the evidence was suggestive only that some patients may benefit from videotaped or audiotaped family messages, massage, pet therapy, commands issued at the patient's comprehension level, bright light, and cognitive remediation.

Direct interventions primarily for cognitive enhancement

This section reviews interventions such as Reality Orientation and Reminiscence therapy as well as interventions focusing on specific cognitive domains such as memory.

Reality Orientation (RO) is based on the assumption that presentation of time, place and person-related information will reduce confusion and lead to new ways of functioning that can compensate for lost behaviours. Studies of RO as an intervention for dementia were reviewed.¹⁷ It was concluded that there were positive effects of RO on both **cognition** and **behaviour** but it was difficult to determine which aspects of RO may be beneficial given the considerable variation in length, duration, content of sessions and degree of social activity. It is recommended that future studies examine the long-term benefits of this intervention as well as the role of social activity as a useful component of RO.¹⁸

Reminiscence therapy involves recalling or reviewing of events in a person's life, either alone, or with another person or group of people. An analysis of research concluded that its effectiveness in improving **cognition** and **behaviour** had not been conclusively demonstrated¹⁹ and the reviewers strongly urged that more research be done examining the value of reminiscence therapy.

Another review,¹⁸ which included a broader selection of studies, concluded on the basis of four studies that Reminiscence therapy showed only minor improvements in *depressive symptoms* and *gross cognitive function* but did improve staff-resident interactions.

Finally, one review of over 13 published reports on memory training¹⁸ concluded that more *comprehensive cognitive interventions* (e.g., training sessions that included conversations, memory exercises, and problem-solving techniques) fared better than specific memory training and that they were most effective with mildly impaired individuals. Thus, direct memory training may not be effective in people with dementia as the disease progresses.

Interventions for family caregivers

A study of spousal caregivers of people with AD examined the effectiveness of an intervention that consisted of six counseling sessions over four months, followed by membership in weekly support groups as well as continuous availability of counselors.²⁰ This intervention was compared to a no-treatment control group. Spousal caregivers who were part of the intervention group were able to care for their relatives at home for a longer period of time than the control group.

In one home-based program,²¹ a comprehensive cognitive skills remediation was implemented. This involved the training of ten family dyads (caregiver plus patient) who were compared with a non-treatment group of six family dyads. The program involved eight months of practice (one hour per day, six hours per week). Patients maintained their levels of cognitive and behavioural functioning and improved emotionally. Benefits extended to the emotional well-being of caregivers. In another study,²² both patients and carers showed significant improvements in depression symptoms in a randomized trial examining the effects of two behavioural treatments (patient pleasant events and caregiver problem solving) as compared to wait list and regular treatment control groups. A seven-week psychoeducational intervention for carers of people with dementia²³ was successful in reducing carers' negative reaction to disruptive behaviours and in reducing caregiver burden but showed no decrease in

disruptive behaviours by patients. On the other hand, a three-month psychoeducational intervention for family caregivers did result in a reduction in agitation and anxiety in the care.²⁴

The American Academy of Neurology⁷ considered psychoeducation caregiver training and support groups to be practice guidelines in that they may benefit caregivers of persons with dementia and may delay long-term placement, whereas computer networks, telephone support programs and respite services were considered practice options because the evidence for their effectiveness was judged to be inconclusive or uncertain.

Long-term care staff education

There are many reports in the literature describing behaviour management education programs for family and professional caregivers; however, studies demonstrating feasible and effective education strategies on clinical outcomes are limited.¹⁶ Various education programs for caregivers have been effective in reducing the use of drugs for behavioural symptoms²⁵ and in reducing target behaviours,¹⁶ including aggressive behaviours.²⁶ Long term benefits of these programs on clinical outcomes have not been demonstrated.¹⁶ It is important to note that educational programs evaluated in the United States must be interpreted in the context of legislated guidelines that are linked to reimbursement, a powerful motivator for change.

Environmental interventions

The goal of environmental interventions for people with dementia is to maximize function, safety and dignity while minimizing confusion within the constraints imposed by their illness.²⁷ Lawton²⁸ hypothesized that the less competent an individual is, the more the environment accounts for the individual's behaviour. Therefore, with declining cognitive function, the environment plays an increasingly therapeutic role in dementia care.^{29, 30, 31} However, the interactions between long-term care residents with dementia and their environment are complex and difficult to study.

Design features that have been studied and found to be beneficial include: smaller sized units; separate units for residents with dementia; non-institutional (or homelike) design, especially in dining rooms; avoiding over-stimulation or under-stimulation; increased lighting; camouflaged exits; access to outdoor therapeutic gardens; visible toilets to improve continence; and non-institutional, functional, quiet and warm rooms for bathing.³²

Relocating people with dementia results in increased disorientation and confusion. However, relocation is often necessary within long-term care facilities in order to meet the changing care needs of the residents, and to allow for renovation and repair to the facility. Relocating long-term care residents together as intact units has been shown to have less adverse effects.^{33, 34} Relocation in order to provide respite care has been recommended to supplement home care since adverse effects are insignificant.³²

Pharmacological treatments

Pharmacological treatment of cognitive symptoms

The current mainstay of treatment for mild to moderate AD focuses on the use of drugs known as acetyl-cholinesterase inhibitors (AChE-Is). All AChE-Is result in small but statistically and clinically significant improvements in cognitive function, activities of daily living and overall functioning in patients with mild to moderate AD.³⁵ However, not all patients with AD benefit from AChE-Is. Although these drugs do not prevent disease progression,³⁶ long term treatment with AChE-Is may delay nursing home placement and mortality but the evidence for this is preliminary.^{37, 38, 39} There is also some evidence to suggest that AChE-I response may be enhanced by estrogen replacement therapy in women⁴⁰ and that AChE-Is may be helpful in managing disruptive behaviours in AD.^{41, 42} The effect of AChE-Is in patients with severe AD is being studied. A small case series showed that AChE-Is may be beneficial in reducing hallucinations in patients with dementia associated with Lewy Body Disease (a cause of dementia similar to Alzheimer's disease with visual hallucinations and Parkinson's symptoms)⁴³ but these findings need to be replicated with larger samples.

In a re-analysis of multiple studies, Ginkgo biloba (a plant-based natural remedy) was noted to result in small but definite improvements in cognitive functions but inconsistent benefits in overall functioning.⁴⁴ Other pharmacological interventions that may have small positive effects on cognitive function but are of questionable clinical benefit in AD include selegiline, hydergine, cerebrolysin, nimodipine, idebenone, nicergoline, vincamin, and nicotine.^{7, 36} Drugs that appear to slow cognitive and/or functional decline in AD include vitamin E and possibly selegiline, however not in combination.⁷ Estrogen therapy in women and non-steroidal anti-inflammatory drugs (such as ibuprofen and aspirin) may be protective against the development of AD⁷ and further study is currently underway in these promising areas. Some other drugs, such as cholinergic precursors and muscarinic agonists have not been shown to be beneficial in the treatment of AD.

There are currently no clearly beneficial treatments available for vascular dementia (VD).⁷ While a few agents have been shown to have small positive effects in some studies (pentoxifylline, hydergine, oxiracetam, cylandelate and flunarizine)^{36, 45} these effects have either not been demonstrated to be clinically significant or have not been reproducible. Drugs that may possibly slow the progression of vascular dementia include aspirin⁴⁶ and pentoxifylline.⁴⁷

There are currently no clearly beneficial treatments for mixed dementias; Ginkgo biloba may improve cognition and function in unspecified dementia but supporting evidence is weak.⁷

Pharmacological treatment of non-cognitive symptoms

The cognitive and physical impairments associated with AD and other dementias coupled with the psychiatric symptoms (delusions, hallucinations, personality changes and mood disturbances) significantly alter an individual's ability to perceive and respond appropriately to the environment and interactions with others. It is often difficult to differentiate between symptoms of the underlying disease and an individual's psychological reaction to their disease and their surroundings.¹⁸ Prior to initiating pharmacotherapy for behavioural symptoms, the target symptom(s) should be clearly described with its antecedents

and consequences. Internal events or circumstances (pain, illness, medications, fatigue) and external stressors (environment, caregiver approach, level of stimulation) contributing to behavioural symptoms need to be identified and modified, if possible.³⁶ Drugs should only be considered for behavioural symptoms that do not respond to non-pharmacological strategies; are significantly disruptive or put the individual or others at risk; and are generally medication responsive. Behavioural symptoms that respond to medications include delusions, hallucinations, mood disturbances including anxiety, agitation,³⁶ and possibly hypersexuality.⁴⁸ Behaviours that generally do not respond to medications include wandering, exit seeking, hoarding, inappropriate voiding/defecation, disrobing, repetitive questioning, sexually inappropriate behaviour and disruptive vocalization.⁴⁹

Anti-psychotic medications in low doses result in modest improvements in behavioural symptoms in some people with dementia.^{50, 51} A re-analysis of multiple studies looking at anti-psychotic drug use in dementia concluded that 18 out of 100 patients with dementia benefited from these drugs for behavioural symptoms. It does not appear that one anti-psychotic drug is more effective than another;⁴⁰ however, atypical anti-psychotic drugs (e.g., risperidone, olanzepine, and quetiapine) may have fewer adverse effects compared with traditional anti-psychotics.^{7, 36} Patients with dementia associated with Lewy Body Disease appear to be more sensitive to anti-psychotic drugs⁵² necessitating caution with these medications in this patient group. Other medications used to treat agitation, aggression and psychotic symptoms in AD (e.g., anticonvulsants, Selective Serotonin Re-Uptake Inhibitors (SSRIs), benzodiazepines, buspirone) have weak evidence supporting their effectiveness.³⁶ Night-time agitation has been reported to respond to trazadone.^{53, 54} Anti-depressant medications, particularly the SSRIs, have been found to be beneficial in treating depression in AD.⁷ The use of benzodiazepines (minor tranquilizers) should be limited to occasional use for non-psychotic agitation³⁶ as these drugs can worsen cognitive function and increase agitation due to paradoxical reactions.⁵⁵

Medications used to treat behavioural symptoms need to be started at low doses, gradually increased if required, and monitored for effectiveness and the emergence of adverse effects. Adverse effects include worsening cognitive

functioning, sedation, increased agitation, and symptoms resulting from anti-psychotic drugs (tremor, rigidity, stooped posture). Ongoing management of these medications requires establishing the lowest effective dose and attempting to discontinue the medication if it may no longer be required.

Conclusion

Dementia is a serious health and social concern, which is going to increase in magnitude in years to come as the population ages. The development of effective ways to care and treat individuals with dementia is a paramount issue.

This chapter has reviewed psychosocial, environmental and pharmacological treatment to improve cognition and enhance behaviours. It is clear from this review that their effectiveness relates to the etiology and stage of the dementia disorder. Psychosocial and pharmacological interventions aimed at enhancing cognition appear most effective at earlier stages of the disease process when abilities are still preserved. We have shown that psychosocial and environmental interventions are effective in the enhancement of a range of behaviours with people with dementia and should be the first line of treatment before pharmaceutical management is considered. We have also attempted to stress in this chapter the critical need for more research investigations, both in home and institutional settings, which compare the effectiveness of new and existing treatment modalities.

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